# OPERATION: SURVIVE!

## At the Ponce de Leon Medical Center
## Saturday, September 28, 1996
## AGENDA

| | | |
|---|---|---|
| 8:30am - 9:00am | **Registration and refreshments** | Peer Facilitators |
| 9:00am - 9:25am | **Welcome and Introductions** | Allen Thornell, AIDS Survival Project Board of Directors |
| 9:25am - 10:10am | **HIV Overview** | Eddie Young, AIDS Survival Project Board of Directors |
| 10:15am - 10:25am | Break | |
| 10:25am - 11:20am | **Support Groups** | Peer Facilitators |
| 11:20am - 11:30am | Break | |
| 11:30am - 12:25pm | **Antiretrovirals & Emerging Technologies** | Edith Biggers, M.D., Fulton County Health Department, Ryan White Clinic |
| 12:25pm - 1:00pm | Lunch | |
| 1:00pm - 1:15pm | **Substance Abuse & Safer Using** | Alicia Culver, Associate Director, AIDS Survival Project |
| 1:15pm - 2:15pm | **Disability** | Mickey Alberts, Disability Adjudication Section, DHR and Tina Skinner, Social Security Administration |
| 2:20pm - 2:30pm | Break | |
| 2:30pm - 3:30pm | **Conscious Living/Conscious Dying Break Out Groups**<br>**OR**<br>**Open Discussion Group** | Brandon Abernathy or Joe Greenwood<br>Terry Roberts |
| 3:30pm - 3:40pm | Break | |
| 3:40pm - 4:10pm | **Access to Health Care** | Peter Stinner, Mercy Mobile Health Care |
| 4:10pm - 4:25pm | **Housing Issues** | Tracey Upton, AIDS Legal Project |
| 4:25pm - 4:35pm | Break | |
| 4:35pm - 5:20pm | **Nutrition** | Beverly Hernandez, M.S.R.D. |
| 5:20pm - 5:30pm | Break | |
| 5:35pm - 6:20pm | **Support Groups** | Peer Facilitators |
| 6:20pm - 6:45pm | **Closing** | Joe Greenwood, *Survival News* Editor AIDS Survival Project |

guilt → motivation
regret → learning

27 September 1996

OVER>

# OPERATION: SURVIVE!

## At the Ponce de Leon Medical Center
## Sunday, September 29, 1996
## AGENDA

| | | |
|---|---|---|
| 9:30am - 10:00am | **Check in and refreshments** | Peer Facilitators |
| 10:00am - 10:05am | **Welcome Back** | Alicia Culver |
| 10:05am - 11:00am | **Prevention and Treatment of Opportunistic Infections** | Tom Geckler, P.A., Grady Infectious Disease Program |
| 11:00am - 11:10am | Break | |
| 11:10am - 11:55am | **Support Group** | Peer Facilitators |
| 11:55pm - 12:05pm | Break | |
| 12:05pm - 1:20pm | **Legal Issues** | John Warchol, J.D, AIDS Legal Project |
| 1:20pm - 1:55pm | Lunch | |
| 1:55pm - 2:15pm | **Dental Care** | Tom Sparkman, DDS |
| 2:15pm - 2:35pm | **Clinical Trials** | Anjanette Latimore, ARCA |
| 2:35pm - 2:50pm | **Being Your Own Advocate** | Jeff Graham, Executive Director, AIDS Survival Project |
| 2:50pm - 3:00pm | Break | |
| 3:00pm - 3:50pm | **Complementary Therapies** | Bobby Dunning, R.N. F.N.P., AIDS Treatment Initiatives |
| 3:50pm - 4:00pm | Break | |
| 4:00pm - 5:15pm | **Safer Sex for Men**<br>**OR**<br>**Women's Medical Issues & Safer Sex for Women**<br>**OR**<br>**Issues for Partners, Families and Friends** | David Salyer, AIDS Survival Project<br>Karen Link, RN., AIDS Survival Project<br>Michaela McKahary, AIDS Survival Project<br>Karen Ashley, Sisterlove, Inc<br>Randy Beggs, M.S., N.C.C. |
| 5:15pm - 5:25pm | **Break** | |
| 5:25pm - 6:25pm | **Support Groups** | Peer Facilitators |
| 6:25pm - 7:00pm | **Closing** | Joe Greenwood |
| 7:00pm | **Evaluations and Cake** | |

27 September 1996

AIDS
# SURVIVAL
PROJECT
**A COALITION OF PEOPLE AFFECTED BY HIV**

## Mission Statement

*We are diverse people living with HIV, united to promote self-empowerment and enhanced quality of life for HIV affected individuals through advocacy, education, peer support and treatment activism.*

## AIDS Survival Project Services

- Advocacy
- *Survival News*
- Operation Survive
- Peer Counseling
- Support Groups
- Treatment Forums
- Treatment Resource Center

***This program is dedicated to the memory of Operation: Survive! creator Roy Griffin***

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The “Operation: Survive!” logo, name, curriculum and workbook were developed and designed by Roy Griffin, Jamey Rousey, Alicia Culver, Michael Cook, Chris Miller, Sonny Magill, Trip McCord, Don Harwell, Lola Halpin, Joe Wheeler, Bobby Dunning, Robert Rockwell, Dave Wagner, Jeff Graham, Dawn Averitt-Dougherty, Maureen Dinges, Liz England-Kabalka, Chip Rowan, Anita Kimmons, Mark King, Thom Beltramba and Steve Moore and are owned by AIDS Survival Project. Additional material provided by Project Inform, BETA, Test Positive Aware Network, AIDS Legal Project, Seattle-King County Department of Public Health, Grady Infectious Disease Program, Gay Men's Health Crisis and others as footnoted. Please contact AIDS Survival Project for permission to duplicate any or all portions of this workbook.

**Thirteenth edition**
**September 1996**

# DISCLAIMER

AIDS Survival Project provides the "Operation: Survive!" workbook as an informational resource for individuals living with HIV and AIDS. Persons living with HIV/AIDS, as well as their medical advisors, must recognize that treatment issues relating to HIV/AIDS are complex and that information regarding treatments may change from day to day. It is helpful for individuals to gather as much information as possible concerning a particular therapy or treatment before making a decision whether or not to use such treatment(s) or therapy. Such decisions need always to be made in consultation with a physician who is knowledgeable about HIV/AIDS and the therapies or treatments in question.

AIDS Survival Project does not recommend, advocate or endorse the use of any particular treatment, therapy, or course of action described in this workbook. AIDS Survival Project therefore does not accept the risk of, or responsibility for, any damages, costs or consequences of any kind whatsoever which may arise or result, either from use or reliance on the information contained herein, or due to any errors contained herein. Persons relying on the information contained in this workbook must do so at their own discretion.

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## APPENDIX B

AIDS TREATMENT INITIATIVES COMPLEMENTARY & ALTERNATIVE TREATMENT AND THERAPIES GUIDE ........ i

# ACCESS TO HEALTH CARE

# WHO IS PRIMARILY RESPONSIBLE FOR YOUR HEALTH CARE? [1]

"Who is primarily responsible for your health care?" This question seems simple enough, however people living with HIV/AIDS often cannot come up with the answer. The job has been given to doctors, parents, lovers, friends, insurance companies and even AIDS service organizations. The fact is that you, and no one else, are primarily responsible for your own health care. The others are simply resources you access as you care for yourself in the face of an HIV/AIDS diagnosis. As the person primarily responsible for your health care, the most important relationships you will have are the ones between you and your health care providers. Health care providers are not only doctors, but also include pharmacists, chiropractors, registered dieticians, massage therapist, psychotherapists, etc.

Before you look at health care, you have to decide what health is. Each of you is a body, mind, and spirit that work together to make up who you really are. The technical term is BIOPSYCHO-SOCIAL BEING. You have to look at all three of these areas if you are working toward optimal health.

The most important factor to remember in your patient/provider relationship is that your health care provider - despite the degrees and titles - is NOT primarily responsible for your health care. You are! Your health care providers are simply resources - true, they are critical ones - for you to access as you take care of your own health needs.

With that in mind let's de-mystify the medical profession. Doctors may be caring, devoted, helpful human beings; they are not gods, psychics or magicians. So don't allow intimidation to silence you when it comes to the relationship between you and your doctor. Health care is a market commodity (i.e. a service you pay for like car repair) and you have rights as well as responsibilities as a consumer. You pay your health care provider for his/her expertise and advise.

One of your most fundamental rights is to be informed by your doctor about anything that has a bearing on your health care. This right to be informed includes, but is not limited to:

**1. Diagnostic Information.**

It is your right to be told by your doctor of any diagnosis that he/she makes about your condition of health

**2. Testing Information.**

It is your right to be informed about why you are being given a test (urine, blood, or other) in the first place; this should be explained by your doctor. Your doctor should also explain the results - what the outcome of the test was, and what that means to you. A booklet outlining the most commonly ordered lab tests is available at the AIDS Survival Project Treatment Resource Center.

**3. Medication/Therapy Information.**

It is your right to be informed by your doctor about any medication/therapy prescribed for you. You should know what the medication/therapy is supposed to do (prevent PCP, slow down the virus, get rid of thrush, etc.), and what side effects the drug might have, if taken at the same time with other medications, vitamins, and therapies, if mixed with drugs or alcohol, etc. You should also be clearly informed about when to take the medication and in what dosages, to assure proper usage and benefits.

**4. Experimental Protocols Information.**

It is your right to be informed by your doctor of any experimental treatments that he/she is aware of and for which you might be eligible for. Along with this information your doctor should also explain how to access this treatment and any risks which might be involved.

**5. Informed Consent.**

Anytime you agree to a test other than a routine blood drawing (e.g. spinal tap), your doctor is required, by law, to give you all the information on the risks and benefits of the procedure before asking you to sign the consent form.

**Along with the right to be informed comes the additional responsibility to:**

**1. Inform Your Doctor.**

It is your responsibility to inform your doctor of anything that you know of which might have a bearing on your health. Your doctor should know of any holistic "self-help" type therapies you practice (macrobiotics-diets, vitamin packs, acupuncture, underground "AIDS" medications, etc.), as well as any habits/practices that could negatively affect your health (smoking, drug/alcohol usage, etc.). You should also inform your health care providers of all other health care providers that you use. Fragmentation is defined as seeing several providers for the same problem but not telling them what the other is doing. It is a dangerous thing for you because you might be given two medications that have serious effects with each other.

**2. Educate Yourself.**

It is your responsibility to educate yourself about anything that might have a bearing on your health. There are many articles, books, video tapes, etc. on the diagnosis of opportunistic infections, testing, medication/therapies, and experimental treatments. You cannot depend only on your physician to provide you with all the information available. It is a good idea to get on mailing lists, participate in treatment forums, support groups and social activities (e.g. PWArties at AIDS Survival Project), get involved with community agencies, read articles written on AIDS related subjects, etc. You can never be well enough informed unless you are willing to learn things for yourself.

Another of your rights is the right to have any question you may have regarding your health answered by your doctor. You will be given a wealth of information by your doctor and through your own research, and some of this information may not always be in the easiest terms to understand. You have the right to have your questions answered; however, along with that right comes the responsibility to ASK questions. Many people living with HIV/AIDS do not get their questions answered, because they do not ask them. Questions don't hurt, ignorance does.

Once you're informed and have had all of your questions answered, you have yet another right. That right is your choice to agree or disagree with your health care providers' advice. More simply put, it is the right to decide what treatments, medications, therapies, etc. you will or will not be willing to use. Know this - it's your decision because it's your body.

The decision is yours to make. It is your right. If you feel a drug could potentially be harmful and you are not willing to take the risk, "just say no". However with this right comes the awesome responsibility to:

**1. Inform Your Doctor.**

Explain why you have chosen to not go along with his/her advice and discuss this with him/her. There may be other answers. Never mislead your doctor into thinking you're taking a medication/treatment/therapy when you are not; likewise never mislead your doctor into thinking you have quit taking your medication, smoking, etc., if you still are. Hiding the truth can have some consequences for your health that you may not want.

**2. Take Responsibility for Your Decision.**

If somewhere down the line you find out your decision was the wrong one, you have to take the responsibility. There is no one else to take that responsibility.

**3. Remember You Can Always Change Your Mind.**

New treatment information is coming out every day. Stay aware and up to date on new treatments. If what made you not try something changes, you can change your mind and try it.

Finally, and most importantly, you have the right to receive quality health care. Demand no less. Again, with this right comes the responsibility to fully cooperate in that health care process. As with any relationship, both parties must fully participate for the relationship to work. Remember you are primarily responsible for your own health care, you must work with your doctor, exercising your full rights and responsibilities, to insure that you receive the quality health care you deserve.

**KNOWLEDGE = POWER**
**ACTION = LIFE**

# PATIENT'S BILL OF RIGHTS AND RESPONSIBILITIES [2]

## EACH PATIENT RECEIVING SERVICES SHALL HAVE THE FOLLOWING RIGHTS:

1. To receive appropriate, coordinated, and quality services without discrimination because of age, race, religion, sex, handicap, national origin, or sexual orientation.
2. To the extent consistent with appropriate health care, to be informed of treatments, procedures, and those aspects of his/her condition that relate to health services provided, including alternatives, in terms he/she can understand.
3. To actively participate, where possible, in the planning, evaluation, and revision of his/her plan of care and to receive appropriate instruction and education regarding the plan.
4. To be informed and to give consent prior to any treatments that are experimental in nature and prior to participation in ant research activities.
5. To be treated with respect, consideration and full recognition of dignity and individuality including privacy in treatment and care.
6. To access in formation in his/her own clinical record upon request and in agreement with his/her care provider.
7. To voice grievances and recommend changes in plan of care free from restraint, discrimination, or coercion.
8. To approve or refuse release of clinical records to outside agencies, insurers, or health care providers.

## EACH PATIENT RECEIVING SERVICES SHALL HAVE THE FOLLOWING RESPONSIBILITIES:

1. To provide accurate, complete health information concerning past illnesses, hospitalizations, medication, allergies, and other pertinent items.
2. To assist care providers in developing and maintaining a safe health care environment.
3. To participate in the development of a plan of care and , then, make best efforts to adhere to the plan.
4. To make all efforts to keep appointments and to inform care providers when unable to keep a scheduled visit.
5. To inform care providers of any changes in care provision, medication changes, or changes in health status.
6. To inform care providers regarding any concern or problems he/she may have.

# ALL ABOUT HEALTH CARE PROVIDERS [3]

## PART ONE: CHOOSING A PROVIDER

Choosing a health care provider is a very important decision. Check with friends who are in the same health situation, and see if they have found health care providers who are HIV and AIDS knowledgeable. You can also contact the AIDS Survival Project. You will be given the names of at least three health care providers within a 20 mile radius of your home who have had experience treating people with HIV and/or AIDS.

Unfortunately, some health care providers believe that HIV and AIDS are always fatal and that "nothing can be done." If your health care provider is such a person, find a new one.

Once you have gathered a few names, you can begin to get in touch with them; there is no need to select the first provider you speak to. Try to set up "consultation visits" with potential providers to meet them in their offices. When you are "interviewing" a potential provider, you may want to include some of the following questions:

- Does someone take backup calls if he/she is on vacation? Who?
- Is he/she affiliated with a hospital?
- Can he/she be reached after office hours?"
- Are there other health professionals in his/her practice who have treated people with HIV and/or AIDS?
- Does he/she respect your right to confidentiality?
- How many HIV patients has she/he had?
- Does he/she have a problem with your sexual orientation? Will he/she accept your definition of family?
- How do they feel about complementary/alternative therapies and providers?

It's a good idea to write down your questions for the provider before you get there. Write down the answers, too, to help you remember what was said. **In the Appendix A Section of this book, you will find a Question Log which you can use to jot down what you want to ask.** This process is very worthwhile. Sometimes people bring a trusted friend with them for support and for a second opinion.

You should feel comfortable talking with your health care provider. Does he or she use words you understand? Does he/she listen to what you say? It's very important that you feel as though your provider is working with you. Treating HIV and AIDS is most successful when done as a team. You should be a part of the team with your provider(s). To make it most effective, listen to what is being said and be sure you get a chance to voice your concerns and desires. If for any reason you are made to feel inferior or unimportant, raise the issue with your provider. If you and he/she cannot resolve your differences, consider finding a new provider.

We are constantly learning more and more about HIV and AIDS. Yet, it is understandable for your provider to be cautious about treatments that a lot of information is not available for. It is also important that he/she be open to new ideas. If you hear of a new treatment, ask your provider. It is possible that he/she hasn't heard of it yet, or hasn't considered it.

Ideally your provider will take the time to find out if the treatment you asked about might be right for you. If you feel that your provider isn't taking your questions seriously, you need to let him/her know that immediately. Withholding information from your provider about anything can only harm the trust in your relationship, and potentially make his/her diagnosis less accurate.

At the same time, you should be very cautious about any provider who claims to have a "miracle cure." Although very drastic measures may seem like a good idea when you are feeling desperate, remember to look before you leap. Consider getting a second opinion before starting any type of treatment with which you are not completely comfortable.

Once you have chosen a primary health care provider, it is very important that you feel comfortable with the person you have chosen throughout your relationship. If at any time you feel as though your relationship with your provider is no longer in your best interest, tell your concerns to your provider.

## PART TWO: HOW TO ASK YOUR HEALTH CARE PROVIDER QUESTIONS

Now that you have a health care provider whom you will be seeing on a fairly regular basis, it's important that you be able to talk freely and clearly with him/her. You deserve the best care possible. The following are some guidelines to keep your relationship functioning at its best.

### 1. Ask Questions.

Write your questions down before you get to the office. If your health care provider isn't answering your questions, or if you don't understand the answer you've been given, speak up. Don't pretend to understand something that you don't. The only person who gets hurt in that situation is you. If you feel your health care provider is hurting your health care, say something. For example, if you are unhappy about your treatment, speak up. Health care providers are not mind readers, and they cannot try to fix something if you don't tell them what it is.

### 2. Be Informed and Rational.

Before saying your opinion about options available to you, be informed and approach your provider in a rational manner. Presenting a treatment option that you have researched and can quote statistics and facts about sounds much more realistic to your provider than expressing the desire to start a treatment you know little about and heard about from a friend.

### 3. Help Your Health Care Provider Help you.

Write down things you think your health care provider should know. **You can use the Event Tracker in Appendix A of this workbook to write down any symptoms you are having.** Don't withhold information out of fear of what your doctor may say and don't try to diagnose yourself.

Be sure that your health care provider is up to date with any and all medication you are taking. This includes vitamins, herbal remedies, and antidepressants that may have been prescribed by a psychiatrist. If you smoke or use drugs or alcohol your health care provider also needs to know this information.

Be sure that your health care provider is also up to date on health problems you may be having that are not HIV-related. This will help him/her provide you with the best care possible.

### 3. Follow Instructions

NEVER stop taking a prescription without first talking it over with your health care provider. Even if your symptoms have stopped halfway through the treatment, it's important to finish your medication; if you don't, your symptoms may return or you may develop a resistance to the medication, then it wont work for you anymore.

**4. Learn To Use the Phone Effectively**

Make sure you know what you want to say ahead of time. As you know, health care providers can be very busy. If you keep your message short, no doubt he/she will appreciate it. If the health care provider is with a patient, you may have to speak to a nurse. Often the nurse can relay your message. If you feel that you must speak with the health care provider, or if you are in pain, say so very strongly. Don't try to do over the phone what should be done in person. If you think you need to make an appointment, then make an appointment. Also remember that bad patients get treated badly . If you are rude and abusive to office staff, you may be in for delays. "Good" patients usually get what they need a lot faster than "bad" ones.

**5. Emergency Room Visits.**

Don't use the Emergency Room as a health care provider's office, except in true emergencies. If you are unsure whether or not what you are experiencing is an emergency, call your health care provider's office and ask. Always ask yourself this question: "If I didn't have HIV, what else could this be?" A sore throat may not be thrush but actually the start of a common cold.

If you don't have insurance or money for regular health care, there are many clinics throughout the state that are funded by the Ryan White Care Act to provide health care without regard to ability to pay. If you need to find one of these clinics, AIDS Survival Project can help. Just call and ask for a peer counselor, (404) 874-7926.

**6. Second and Third Opinions.**

If you are told you need surgery or some treatment that is not widely known about or is still being tested, seek a second or even a third opinion. Don't feel that you are insulting your health care provider by asking him/her for a referral - this is your right as a person receiving medical care. Your health care providers should support your desire to make careful, good decisions.

**7. Educate Yourself.**

It can be very helpful to go to the library, read new journals, buy books. If you don't want to buy the books, call AIDS Survival Project and ask for the Treatment Resource Specialist. They have many books and videos you can check out, as well as all the latest journals. Find out whatever you can about your medical condition and share what you have learned with your health care provider. As much as we'd like to be our health care provider's only patient, often he/she may not have the amount of time that you do to keep up on current information. Be skeptical of miracle cures or drastic treatments you may read about in magazines. More likely than not, these people are more interested in their TV ratings and magazine circulations than in your health. Always check things out. If it sounds too good to be true, it may well be.

**8. Take Care Of All Parts Of You.**

Your health care provider should be sensitive to all of your needs, but he/she cannot and should not fulfill them all. If you need emotional support, consider support groups and/or counseling. Try to have realistic expectations. No one person can provide all of the services you need, especially if your need is outside his/her field.

Going to your health care provider doesn't have to be the unpleasant chore it was when you were a child. If you are taking an active role in your health care, office visits can be productive and rewarding. Keep the communication with your health care provider open and honest. Remember that you are part of a team; trust your health care provider, and trust yourself. After all, you are your own best ally.

# WHAT IS MANAGED CARE? 4

Managed care is not a new concept. HMO's are examples of managed care, and they've been around for decades. However, millions of Americans who have never considered managed care as an option are suddenly being presented with Health Maintenance Organizations (HMO's) or Preferred Provider Organizations (PPO's) as their only choice.

Managed care is a system in which a patient's care is "managed" to control costs and/or improve continuity of care. Depending on whom you talk to, you will hear very different definitions of the concept of managed care. Regardless, it is here and there are things you need to know about managed care.

In managed care, a primary care physician serves as a "gatekeeper" to all other health care. The primary care physician is contracted to oversee your needs and refer you to medical specialists when he/she deems necessary. If this kind of system is implemented with a great deal of patient concern and quality care, it can be more efficient and cost effective than the "fee for service" system in which patients see a physician when a problem occurs and insurance (private or government funded like Medicaid and Medicare) pays for it.

However, the biggest concern with the managed care system is that profits can become the prime motivation rather than quality of care.

It is true that sometimes the "fee-for-service" system can be wasteful and inefficient. Malpractice lawsuits encourage doctors to protect themselves by doing every test known to humankind, rather than just what is necessary. As well, as we've seen in Atlanta, some doctors have profited enormously from their referrals and excessive use of tests. These truly are abuses of the system, for which there must be some remedy. Managed care was created as a remedy, but with its emphasis on cost-cutting may create abuses of its own.

One of the terms you will hear in a managed care system is capitated payment (from "per capita" or "per head"). Capitated payment basically means there is a specific rate or fee paid for each person enrolled in the program. If the care provided costs less than the capitated rate, the managed care program makes money. If the care costs more, the managed care program loses money. The less care provided, the more money made. This leaves room for profit minded administrators to make decisions and control your health care; not you, your doctor or hospital.

# THE ALPHABET SOUP OF HMO'S & PPO'S: [5]

Deciphering the difference between HMO's, PPO's, and the like is as confusing as sorting out the difference between AZT, 3TC, D4T, ddI, etc. Some definitions might be handy:

### HMO: Health Maintenance Organization.

HMO's can contract with independent medical groups which provide care to HMO patients for a capitated fee. HMO's can also employ their own staffs who are exclusive to that HMO. Usually with HMO's you have very small or no co-payments for office visits and prescriptions. However, the trade off you make is usually limited choice of physicians and decreased access to specialty providers. Usually, if you want to see a physician out of the plan, the HMO will not pay any of the costs. As well, it is the primary care physician that decides when and who you need to see for special care (like treatment of HIV).

### PPO: Preferred Provider Organizations.

PPO's are a network of independent physicians that are contracted by the plan. If your physician is part of the plan, it will pay most or all of the costs. If your physician is not part of the plan, you must pay a larger portion of the bill. Typically with a PPO, you have more options in choosing physicians as well as determining when you need specialized care, which is extremely important when dealing with a chronic illness. The drawback is that the out-of-pocket cost to you is usually greater.

In both types of managed care, the physicians get plenty of patients, but are paid less for each visit and procedure.

We've seen time and time again with managed care that patients who have the time, energy and support systems to fight for what they need, can get the care they need, but it is not easy. Too many people have to settle for what they can get.

# CHECKLIST WHEN CHOOSING BETWEEN MANAGED CARE ALTERNATIVES [6]

- Do they have physicians with experience treating people living with HIV?
- Do they have a standard of care for treating HIV/AIDS? (Find out the specifics to see if it meets your requirements)
- Will you have access to experimental, off-label and expensive medications and treatments?
- How much home care can you get? (What are the limits?)
- Do they have patient advocates to help you with problems?
- Do they have a mechanism for input from the community? (Patient committees, etc.)
- Do they have social workers that can help you navigate through the bureaucracy?
- What are your "out of plan" options?
- If you do have "out of plan" options, what will your costs be?
- Will they cover mental health services? What are the limits? How can you access these services?
- What will you have to do to see a specialist? (Remember, that in some plans gynecologists are considered specialists, as are dermatologists, oncologists, dentists, psychologists, etc.)
- Do they have a grievance procedure to address your concerns, how long will this take?
- How often can you switch plans and what is the process? (With some plans, you can only make changes annually)

With the rapid changes occurring in health care delivery, there are few consumer protections currently in place. As always, the more you are involved in the process, the more you can ensure protection and access to care for all people living with HIV.

# FOOTNOTES

1. by Jamey T. Rousey
   *The NAPWA NEWS*, January 1991

2. by Mercy Mobile Health Care
   Central Health Center Clinic II
   at AID Atlanta

3. Seattle-King County Department of Public Health,
   AIDS Prevention Project
   (206)296-4999

4. by Alicia A. Culver
   *The Survival News,* February 1996

5. by Alicia A. Culver
   *The Survival News,* February 1996

6. by Alicia A. Culver
   *The Survival News,* February 1996

BEING YOUR OWN ADVOCATE

**This section revised by R. Dunning, Jr., R.N., M.N., C.S.**
May 1994
Updated by Alicia A. Culver
September 1996

# BEING YOUR OWN ADVOCATE

# BEING YOUR OWN ADVOCATE

**Things to Keep in Mind:**

- You know yourself better than anyone else, if something doesn't feel right, sound right, or seem right— it probably isn't.

- Asking questions is a good thing! Often advocacy is nothing more than clearing up a misunderstanding.

- Write things down, and keep good records. These are your proof of what was said, what was promised, and what you've asked for. Make notes of phone calls, meetings, and people you speak with.

- Know where to go for help. If you feel you need assistance with a problem, feel free to call AIDS Survival Project, AIDS Legal Project, or consult with your own attorney.

- Remember you have legal protection to ensure confidentiality of your medical condition and a right to access of health care and public facilities.

- Don't sign something unless you know what exactly you are signing.

- **Knowledge = Power.** Know what your protections are. Read things such as insurance documents, non-discrimination clauses, and company disability policies carefully.

# LE MANIFESTE DE MONTREAL

## DECLARATION OF UNIVERSAL RIGHTS FOR PEOPLE LIVING WITH HIV

### Preamble

HIV disease (infection with HIV with or without symptoms) is a worldwide epidemic affecting every country. People are infected, sick and struggling to stay alive. Their voices must be heard and their special needs met. This declaration sets forth the responsibilities of all peoples, governments, international bodies, multinational corporations, and health care providers to ensure the rights of all people living with HIV disease.

DEMANDS

1 All governments and all international and national health organizations must treat HIV disease aggressively and positively and as a chronic, manageable condition. Ensuring access and availability of treatment must be part of the social and moral obligations of governments to their citizens.

2 Governments must recognize that HIV disease is not highly infectious. Casual contact presents no threat of infection, and irrational fears of transmission must be fought.

3 An International code of rights must acknowledge and preserve the humanity of people with HIV disease.

This code must include:

a) anti-discrimination legislation protecting the jobs, housing and access to services of people with HIV disease;

b) active involvement of the affected communities of people with HIV disease in decision-making that may affect them;

c ) guaranteed access to approved and experimental drugs and treatments, and quality medical care;

d) the right to anonymous and absolutely confidential HIV antibody testing. Pre- and post-test counseling must be available;

e) the right to medically appropriate housing;

f) no restriction on the international movement and/or immigration of people with HIV disease;

g) full legal recognition of lesbian and gay relationships;

h) no mandatory testing under any circumstances;

i) no quarantine under any circumstances;

j) protection of the reproductive rights of women with HIV disease, including their right to freely choose the birth and spacing of their children and have the information and means to do so;

k) special attention to the unique problems and needs of intravenous drug users, including provision of substance-abuse treatment on demand;

l) special attention to the unique problems and needs of prisoners with HIV disease and guaranties that they receive the same standard of care and treatment as the general population;

m) the right to communication and all services concerning HIV disease in the language (written, signed or spoken) of his/her choice, through and interpreter if necessary;

n) the provision of reasonable accommodation in services and facilities for disabled people;

o) catastrophic/immunity rights - the guaranteed right of people faced with a life-threatening illness to choose treatments they deem beneficial for themselves.

4 A multi-national data bank to make available all medical information related to HIV disease must be created. This includes all data concerning drugs and treatments, especially basic bio-medical research and initiation of any progress of clinical trials.

5 Placebo trials must be recognized as inherently unethical when they are the only means of access to particular treatments.

6 Criteria for the approval of drugs and treatments should be standardized on an international basis so as to facilitate worldwide access to new drugs and treatments.

7 International education programs outlining comprehensive sex information supportive of all sexual orientations in culturally sensitive ways and describing safer sex and needle use practices and other means of preventing HIV transmission must be made available.

8 The unequal social position of women affecting their access to information about HIV transmission must be recognized and also their rights to programs redressing this inequality, including respects for women's rights to control their own bodies.

9 Industrialized nations must establish an international development fund to assist poor and developing countries to meet their health care responsibilities including the provision of condoms, facilities for clean blood supply and adequate supplies of sterile needles.

10 It must be recognized that in most parts of the world, poverty is a critical co-factor in HIV disease. Therefore, conversion of military spending worldwide to medical health and basic social services is essential.

# TIPS ON CONTACTING YOUR ELECTED OFFICIALS

**To call your member of congress in Washington:**

Senate: (202) 224-3121
House: (202) 225-3121

## TIPS ON WRITING TO A MEMBER OF CONGRESS

**Recommended forms of salutation:**

Dear Senator_________ or Dear Representative_______________

Note: When writing to the Chair of a Committee of the Speaker of the House or the Majority Leader of the Senate, it is proper to address them as:

Dear Mr. Chairman/ Dear Madam Chair/ or Dear Mr. Speaker/ or Dear Mr. Leader

**Selected Guidelines on Writing a Letter:**

- ✔ Use personal or business stationary with a correct return address. Envelopes sometimes get thrown away before the letter is answered.
- ✔ Confine each letter to one topic or piece of legislation. Because of the volume of correspondence members receive, it is not unusual for different staff to be assigned to preparing replies to specific issues.
- ✔ Keep your letter brief. Making your point in one page is ideal.
- ✔ Identify your organization. If you are writing on behalf of your organization say so; and, if you are constituent, let the member know.
- ✔ State your purpose, and/or the reason for your letter, clearly within the first paragraph. When you are writing about a specific piece of legislation, a House bill is usually identified as H.R._____ and a Senate bill is S.______.
- ✔ Personalize your message. If you are writing about a legislative proposal, explain how it affects you, your family, your community or your special interest. Personal examples that illustrate your point have a powerful impact. Be factual. If you have data, use it. If you have sources of data, share the information.
- ✔ Be specific about the action you want the member to take. IF you want information, ask for it. If you want the member to vote a certain way or cosponsor legislation, be specific and direct.

- ✔ Keep a positive attitude. Never assume your letter will not be read or will be treated as unimportant. Members and their staff are strongly influenced by both the contents and the volume of correspondence they receive.

## ADDRESSING CORRESPONDENCE:

**To A Senator:**
The Honorable ( insert name)
United States Senate
Washington, D.C. 20510

**To A House Member:**
The Honorable( insert name)
U.S. House of Representatives
Washington, D.C. 20515

# GEORGIA'S UNITED STATES CONGRESSIONAL DELEGATION

## SENATE:

Honorable Sam Nunn
United States Senate
Washington, DC 20510
(202) 224-3521
(404) 331-4811

Honorable Paul Coverdell
United States Senate
Washington, DC 20510
(202) 224-3643
(404) 347-2202

## HOUSE OF REPRESENTATIVES:

**District 1**
Honorable Jack Kingston
United States House of Representatives
Washington, DC 20515
(202) 225-5831
(912) 352-0101

**District 2**
Honorable Sanford Bishop
United States House of Representatives
Washington, DC 20515
(202) 225-3631
(912)741-2221

**District 3**
Honorable Mac Collins
United States House of Representatives
Washington, DC 20515
(202) 225-5901
(404) 603-3395

**District 4**
Honorable John Linder
United States House of Representatives
Washington, DC 20515
(202) 225-4272
(404) 936-9400

**District 5**
Honorable John Lewis
United States House of Representatives
Washington, DC 20515
(202) 225-3801
(404) 659-0116

**District 6**
Honorable Newt Gingrich
United States House of Representatives
Washington, DC 20515
(202) 225-4501

**District 7**
Honorable Bob Barr
United States House of Representatives
Washington, DC 20515
(202) 225-2931
(404) 429-1776

**District 8**
Honorable Saxby Chambliss
United States House of Representatives
Washington, DC 20515
(202) 225-6531
(912) 475-0665

**District 9**
Honorable Nathan Deal
United States House of Representatives
Washington, DC 20515
(202) 225-5211
(404) 535-2592

**District 10**
Honorable Charlie Norwood
United States House of Representatives
Washington, DC 20515
(202) 225-4101
(706) 733-7066

**District 11**
Honorable Cynthia McKinney
United States House of Representatives
Washington, DC 20515
(202) 225-1605
(404) 244-9570

# SIX YEARS AND COUNTING: AN ACT UP/ATLANTA CHRONOLOGY

The following chronology acknowledges that ACT UP is forever indebted to the literally hundreds of individuals and organizations that have supported our work to fight discrimination against lesbians, gays, people of color, and all people affected by HIV/AIDS. We would especially like to thank the Atlanta Chapter of the National Association of People with AIDS (now known as AIDS Survival Project), without whose help many of the following actions would never have happened. This list contains the highlights of some of our most memorable actions. It does not take into account the hundreds of "zaps", condoms distributions, and educational actions that have brought HIV/AIDS issues and information to tens-of-thousands of local people through grassroots action and mobilization. Together, we can make a difference.

**March 1987:** ACT UP is born after a speech by Larry Kramer at the Lesbian and Gay Community Services Center in New York.

**August 1, 1988:** ACT UP/Atlanta is born as Atlantans are inspired after participating in ACT UP/New York demonstrations outside of the Democratic National Convention. Within the first week, ACT UP was off and running with demonstrations at AID Atlanta (to guarantee that the concerns of PWAs were heard during their board meeting), a picket of an appearance by Oliver North, and banners "mysteriously" appear on area overpasses and railroad bridges condemning Circk K's policy of not paying health insurance claims that are the result of "personal lifestyle decisions"—specifically AIDS.

**August 27 and September 3, 1988:** Dozens of cars close down Circle K gas stations by pulling up to the pumps, purchasing 25 cents worth of gas, and paying with a $20 bill. The tactic works and soon Circle K reverses their discriminatory practice.

**September 29, 1988**: A funeral procession down West Paces Ferry Rd. to the governor's mansion ends in a "die-in" and results in the establishment of a state fund to distribute AZT to indigent or uninsured patients.

**December 3, 1988:** ACT UP sponsors the first of what will become many teach-ins to educate local PWA's on their rights and the latest information regarding both traditional and alternative treatment options. This educational process eventually grows well beyond ACT UP, and Atlanta treatment activists earn a place on the national scene for their knowledge and accomplishments.

**April 21, 1989:** ACT UP/Atlanta joins ACT UP/ New York and South Carolina activists to protest a South Carolina provision that would allow PWA's to be quarantined. The proposal is dropped.

**January 8, 1990:** Over three hundred activists from around the nation converge upon the state capitol to protest the Georgia sodomy law. 63 people are arrested for blocking traffic. The next several years see the birth of Atlanta chapters of the Lesbian Avengers, Queer

Nation, GLAAD, and Dykes and Faggots Bash Back, and protests become a common event in the lesbian and gay community. During this time, the annual Pride celebration grows from 5,000 participants to over 100,000.

**January 9, 1990:** The same group of activists descend upon the Centers for Disease Control to protest the CDC narrow definition of AIDS that excludes gynecological illnesses and illnesses that are more common to people of color and children. 49 people are arrested. Soon the CDC begins a series of hearings to determine how to make the definition more inclusive.

**January 19, 1990:** Hundreds of phone calls disrupt business for Galaxy Carpets of Chatsworth, GA in protest of a self-funded health insurance policy that places a cap of $10,000 on benefits paid for AIDS-related expenses. Within hours the company drops the cap.

**March 1, 1990:** After protesting Georgia Assembly Speaker Tom Murphy's bigoted remarks towards lesbians, gays and PWA's, ACT UP is invited to his offices to discuss his actions, attitudes and to gain his support for overturning the Sodomy Law. Although, the law is not overturned, a bill calling for it's repeal reaches the floor of the House—the first and only time reform legislation gets that far.

**June 16, 1990:** For the first time in queer history, protesters arrive in Marietta town square to protest the conviction of an HIV+ man on the charges of attempted murder after he bites a police officer during an arrest.

**July 13-19, 1990:** Members of ACT/UP Atlanta participate in demonstrations at the Sixth International Conference on AIDS held in San Francisco.

**July 16, 1990:** Hundreds of newspaper boxes are covered with bright pink signs with the word "homophobic" printed on them in response to the Atlanta Journal's running of an anti-gay editorial cartoon. In the weeks surrounding the event, dozens of posters condemning columnist Dick Williams bigoted editorials appear around town.

**August 31, 1990:** Atlanta joins the growing movement to boycott Miller beer and Marlboro cigarettes in protest of Phillip-Morris's continued financial support of the infamous Jesse Helms. In the upcoming months, ETC magazine and several local bars take action to support the movement.

**September 13, 1990**: Members of ACT/UP Atlanta join with performance artist Tim Miller to disrupt a speech by then-NEA Chairman William Frohnmeyer for his efforts to censor lesbian and gay related art. Weeks later, Frohnmeyer resigns.

**September 26, 1990:** After an invasion by the membership of ACT UP, the Georgia Department of Human Resources and the local office of the FDA agree to allow ACT UP's participation in the newly formed Georgia AIDS Therapy Information Network. Although originally formed to attack "fraudulent" AIDS therapies, the group is encouraged to provide neutral information on all AIDS therapies as an edutional tool.

**October 12, 1990:** A coalition forms to protest the scheduled appearance of Jesse Helms at the annual convention of Family Concerns (an anti-gay, anti-feminist group sponsored by First Baptist Church). Over 1,500 people circle the church and Helms refuses to make an appearance. Support for the action is given by local publications ETC Magazine and Southern Voice Newspaper. In the following years, ACT UP (along with other pro-choice and queer activists) continues to protest at the annual event disrupting Family Conern's president Nancy Schaeffer's speech to distribute condoms, and by sponsoring pickets, and demonstrating against appearances by George Bush and Jerry Falwell.

**December 3, 1990:** Once again, hundreds of AIDS activist descend upon the CDC to protest the continued exclusion of women from the CDC's definition of AIDS. 107 are arrested, including 52 individuals who take over the office of Deputy Director for AIDS Gary Noble. Two years and dozens of protests later, the CDC revises their definition to include several of ACT UP's demands.

**May, 1991:** A series of protests are launched to force the administration of Grady Hospital to provide funds for the expansion of the Infectious Disease Clinic. Within weeks, 1.5 million dollars is allocated for this expansion, and improved intake procedures drop the waiting period for new patients from six months to two months.

**July 25, 1991:** Two people are arrested as they attempt to overtake the office of CDC head William Roper to protest the CDC's guideline that urges HIV+ health care workers to disclose their status to patients. The action follows months of debate surrounding the supposed threat health care workers pose to patients after the disclosure that a Florida woman (Kimberly Bergalis) tested HIV+ after seeing her dentist.

**July 26, 1991:** Four people are arrested after shutting down the studios of CNN Headline News to protest the wide spread panic surrounding the Kimberly Bergalis story. ACT UP asserts that the media's reporting was biased, and refused to focus upon the fact that the Bergalis infection was an isolated occurrence, and was never proven to be the result of contact with her dentist.

**September 10, 1991**: ACT UP joins forces with GLAAD to protest advertisements by Metro Dental that claim their staff is tested for HIV to "protect" their clients, within days the television ads are pulled from local stations.

**November 9, 1991:** Protests erupt at local Winn-Dixie supermarkerts following their firing of an HIV+ worker. The employee successfully sues for damages, and the food chain releases a statement supporting the employment rights of PWA's.

**November 28-December 1, 1991:** In commemoration of World AIDS Day, a series of actions take place to draw attention to the need for education, prevention measures, and research surrounding AIDS. Actions include the dropping of a half-dozen banners over local highway overpasses, the releasing of several balloon-supported banners at local malls, projecting the words "Stop AIDS" on the side of the Rich's building during the annual lighting of the Christmas tree and the distribution of condoms, educational materials and the release of a 15' x 40' banner at a Falcon's football game.

**February, 1992:** Despite threats of censorship from local TV stations, a political commercial airs which focuses upon AIDS as an important issue in the upcoming presidential primaries.

**Spring , 1992:** Members of ACT-UP distribute condoms and prevention material outside of local high school proms. This marks the beginning of an annual campaign to raise HIV/ AIDS awareness in local youth.

**August 1, 1992:** A 24 hour vigil is planned to call attention to the fact that Grady Hospital has yet to begin renovations and expansion for the soon-to-be Ponce IDP. The demonstration attracts dozens of supporters, and ends after only 12 hours, when the Grady administration reiterates their support for the planned clinic.

**Fall, 1992:** A series of demonstrations take place focusing upon the rising controversy surrounding the planned expansion of the Grady Infectious Disease Clinic. The demonstrations first target the Fulton and Dekalb county commisions who both initially block the proposal, and later target area businesses who file a lawsuit to prevent the clinic's opening. Soon both county administrations pledge their support for the clinic, and the lawsuit is dropped. The clinic opens one year later, on time and under budget.

**October 22, 1992:** A protest at the state Department of Human Resources draws attention to their lack of effective AIDS education materials and their planned implementation of named reporting for all individuals who test HIV+. As a result, ACT UP is invited to participate in the creation of future educational materials, and ultimately the proposal for named reporting is dropped.

**December 1, 1992:** In a joint demonstration with the National Association of People with AIDS (now known as AIDS Survival Project), money is released to fully fund the distribution of AIDS medication to indigent patient in Georgia.

**January 19, 1993:** Local protest of the continuing policy of confining HIV+ Haitian immigrants focus attention on the HIV ban implemented by the US government. Although the ban still stands, the Haitian refugees were eventually released.

**February 9, 1993:** Protests at the office of drug manufacturer Hoffman-LaRoche eventually lead to the establishment of critical drug trials in the Atlanta area.

**July, 1993:** Protests erupt following Atlanta Mayor Maynard Jackson's veto of legislation assuring the partner's of lesbian and gay city employees the same benefit's as their heterosexual counterparts.

**Summer, 1993:** ACT-UP joins forces with local lesbian and gay organizations to protest Cobb County's passage of a resolution condemning the "gay lifestyle."

**August 10, 1993:** The Grady Infectious Disease Program opens at their new site on Ponce de Leon Ave. During the October opening ceremonies, Fulton County Commission chairman, Michael Lomax, credits ACT Up with making this state -of-the-art facility a reality.

**December 1, 1993:** ACT UP sponsors a speak out in the rotunda of the State capitol to draw attention to the continued affects of the AIDS crisis on local individuals.

**December 2, 1993:** Emory University announces that after months of demonstrations and letters of protest, that they will commit to seeking approval as a site for the national AIDS Clinical Trial Group.

**February 17, 1994:** A letter protesting Atlanta's failure to provide approved funding for local AIDS organizations results in the mayor's commitment to reduce bureaucratic red-tape and stream line the funding process.

**Spring, 1994:** ACT UP and AIDS Survival Project (formerly NAPWA) join forces to protest the confinement of an HIV+ man after he tested positive for multiple drug resistant tuberculosis. Several protest result in arrests.

**July 5, 1994:** Demonstrators outside of the Atlanta City Council meeting force the council to release allocated funds for a housing facility for HIV+ individuals.

# CLINICAL TRIALS

# CLINICAL TRIALS

Clinical trials are experimental programs testing drugs which might be helpful to people with HIV infection for treatment or prevention of opportunistic infections (OI's) and treatment of HIV, itself. Some research involves only the study of HIV and its associated OI's with the purpose of increasing the knowledge bases on HIV for future development of treatment options.

Being a part of a clinical research trial is not for everyone, but for some people the chance to access aggressive promising therapies leads them to participate in clinical trials. The screening process for drug trials involves what is called a protocol and it specifies who would be appropriate for a particular study. The qualifications for a particular trial are a 'necessary evil' that must be fulfilled in order to prove that a medication does what it's supposed to do. All persons who qualify and agree to participate in a study are required by law to be given an informed consent that outlines all the potential benefits and possible risks.

If you are considering participating in a clinical trial, you should feel comfortable asking questions. Most people with HIV look into trials because they usually provide access to new therapies that are not widely available. At the end of this section, you will find references for locations that conduct clinical trials, or have information about what trials are underway and where the trials are taking place. If you would like to talk with someone who has participated in a clinical trial before, please call AIDS Survival Project at (404) 874-7926 and ask for a peer counselor.

Your health care provider should have an understanding of current local drug trials and there are several treatment newsletters and directories for you to use. Also, AIDS Survival Project has a Treatment Research Specialist who knows about clinical trials throughout the Southeast and also maintains an extensive library on various HIV-related treatments. Call AIDS Survival Project's Treatment Resource Specialist at (404) 874-7926.

# CLINICAL RESEARCH [1]

Clinical Research Trials not only provides new insights into the treatment of HIV disease, but also give persons early access to promising medications not yet available on the market. For those considering participation in a research study, here are some comments about the structure of clinical trials.

1. Clinical studies (which evaluate the effectiveness and safety of new drugs) are designed to provide answers about when and how to use these new drugs.

2. Participants in clinical trials are closely monitored for their progression to predetermined "endpoints ". In studies of antiretrovirals, common "endpoints" include:

- Changes in laboratory values (CD4 counts, p24 antigen, and measures of viral load).
- Progression to AIDS (the development of an AIDS defining illness in those without a previous AID diagnosis).
- Progression to further opportunistic infections in those who have already developed an AIDS defining illness).
- Progression to death (survival).

3. After data is evaluated (by complex statistical formulas), the publishers of a clinical trial are usually able to make conclusions about the effectiveness of a new drug.

# COMMONLY USED TERMS RELATIVE TO CLINICAL TRIALS

**Clinical Trials:**

Scientific tests of experimental medicine in human beings who volunteer for these studies. Their purpose is to seek information regarding the drugs' safety (Phase I) and efficacy (how well it works) (Phase II/III).

**Phase I Clinical Trials:**

The earliest stage clinical trial for studying an experimental drug in humans who volunteer for these studies. The purpose is to determine the drugs' safety and find the most effective amount of medicine to take (dose-ranging). Phase I trials are generally comparatively small, typically involving 20 to 100 patients and lasting several months. They also provide information about a drugs' pharmacokinetics - how the drug is absorbed, what tissues it reaches and how long it takes to leave the body. Approximately 70 percent of drugs successfully complete phase I.

**Phase II Clinical Trial:**

A more advanced stage clinical trial that follows the Phase I trials. A phase II trial gathers preliminary information to see whether an experimental drug works and to study its side effects. The major purposes are to continue to determine short-term safety and, primarily, effectiveness. Data are often based on laboratory tests that provide quick, but indirect measurements of a drug's effect on disease. Phase II trials often involve up to several hundred people who are randomly assigned to take either the experimental drug or a "control" (the standard treatment for the disease or no treatment at all). Usually the trial is double-blinded, which means no one (not the patient, doctor, researcher or nurse) knows who is getting the drug until the trial is completed and the results are analyzed. About 33 percent of drugs successfully complete phase II.

**Phase III Clinical Trial:**

After a medication has successfully completed Phase I and II the drug is compared to the current 'gold standard' for effectiveness. Phase III studies should conclusively show how well a drug works as compared to other treatments. Examples of Phase III studies are those which compare other nucleoside analogs (i.e. D4T, ddC, etc.) to AZT for effectiveness in treating HIV. Phase III trials typically involve from several hundred to several thousand patients, take place at multiple sites, and may last from 1 to 4 years. They should measure whether a new drug extends survival or otherwise improves the health of patients on treatment (clinical improvement) rather than just provide surrogate marker data. Approximately 25 to 30 percent of drugs successfully complete phase III.

**ACTG:**

ACTG stands for AIDS clinical trial groups (also called ACTU, with "units" instead of "groups"). ACTGs are a network of medical centers throughout the country that conduct federally funded clinical trials of drugs for treating people with HIV infection. ACTGs are sponsored by the National Institute of Allergy and Infectious Diseases (NIAID). Taken together, the ACTGs are the largest trials of drugs for treating HIV infection in the world: they have the largest budgets, the largest number of investigators, and the largest number of participants.

**ACCELERATED APPROVAL:**

Government approval of a new treatment for sale based on early surrogate marker data from clinical studies. The purpose of accelerated approval is to speed the availability of new drugs for life-threatening HIV-related conditions.

**COMMUNITY PROGRAMS FOR CLINICAL RESEARCH ON AIDS (CPCRA):**

A program involving 17 centers that conduct clinical trials related to HIV in community-based settings. Sponsored by the National Institute of Allergy and Infectious Diseases.

**COMPASSIONATE ACCESS:**

When drugs are made available even though not approved by government agencies.

**COMPASSIONATE USE:**

A process for providing experimental drugs free of charge to some patients who have no treatment options. Access is obtained through the patients' physicians. Often, case by case approval must be obtained from the FDA for "compassionate use" of a drug.

**CONTROL ARM:**

The group of participants in a clinical trial who receive standard treatment or a placebo, against which the experimental treatment is compared.

**CONTROLLED TRIAL:**

A clinical study in which one group of participants receives an experimental drug while another group receives either a placebo or an approved standard therapy. When participants do not know which group they are in, the trial is blinded.

**DOUBLE BLIND:**

A trial design in which neither the subjects nor the participating research investigators are aware of which patients are receiving test drugs and which are receiving placebo or other therapy. Believed to promote faster and more objective results, since it eliminates the possibility of bias concerning the test drug's efficacy.

**EFFICACY:**

The strength or effectiveness of a treatment. The ability of a drug to control or cure an illness. Efficacy should be distinguished from activity, which is limited to a drug's immediate effects on the microbe triggering the disease.

**ENDPOINT:**

A category of data used to compare the outcome in different arms of a clinical trial. Common endpoints are severe toxicity, disease progression or fall in surrogate markers like CD4 count, but sometimes death is used as an endpoint. Usually when an endpoint reaches a certain set magnitude of change from baseline, a trial participant is removed from the trial and receives an open-label therapy (either a standard treatment or experimental one being tested).

**EXPANDED ACCESS:**

Refers to any of the FDA procedures (compassionate use, parallel track and treatment IND) that distributes experimental drugs to patients who are failing on currently available treatments for their condition and also are unable to participate in ongoing clinical trials.

**OPEN-LABEL TRIAL:**

A study in which both researchers and participants know what drug a person is taking and at what dose.

**PARALLEL TRACK PROGRAM:**

A system of distributing certain experimental drugs to individuals who are unable to participate in ongoing clinical trials of that drug.

**PLACEBO:**

A “dummy pill,” “sugar pill,” or look alike material containing no medicine, may also be the standard treatment. Used to compare against effects of experimental drugs. In placebo-controlled trials, the control group takes the placebo, while the test group takes an experimental drug. Many such studies are also double-blinded, which means that neither doctors nor patients know who is receiving drug or placebo.

**PLACEBO EFFECT:**

Improvements in health experienced or perceived by people who are taking a placebo.

**PLACEBO-CONTROLLED STUDY:**

A method of investigation of drugs in which an inactive substance or the standard therapy (the placebo) is given to one group of patients while the drug being tested is given to another group. The results obtained in the two groups are then compared.

**PRINCIPAL INVESTIGATOR:**

The head researcher responsible for organizing and overseeing a clinical trial.

**PROTOCOL:**

A detailed plan for the drug trial. The plan may include the trial’s goal, drugs involved, drug dosage levels, methods of drug administration, treatment duration, potential side effects, who and how many may participate, etc.

**RANDOMIZATION:**

The process by which patients in a clinical trial are randomly assigned to different treatments. Randomization minimizes the differences among groups by equally distributing people with particular characteristics among all the trial arms.

**RANDOMIZED TRIAL:**

A trial in which the participants are randomly assigned to receive one of the treatments under study or a placebo.

**SURROGATE MARKERS:**

A laboratory measurement of biological activity within the body that indirectly indicates the effect of treatment on disease state. CD4 cell counts and viral load are examples of surrogate markers in HIV infection.

**TREATMENT INVESTIGATIONAL NEW DRUG (IND):**

An FDA approved program to use an experimental drug that appears to be safe, and may be effective, in a defined group of patients with serious or life-threatening conditions, and who have no satisfactory alternatives. The purpose is to facilitate availability of promising new drugs as early in the drug development process as possible.

# THINKING IT OVER. . .
# IS A CLINICAL TRIAL RIGHT FOR ME ?

Are you thinking about joining a clinical trial? First, get all the facts you need to make your choice, then be sure how you feel about the issues. Here is a checklist that can help.

The first part is a list of questions to ask your doctor and/or the staff of the trial you are looking into. The second part is a list of questions to ask yourself.

## QUESTIONS TO ASK YOUR DOCTOR

### Facts about the study

- What is the purpose of the study?
- Who is running the study?
- Who is paying for the study?
- Who will review the results?
- What treatment(s) may I receive?
- Does the study use a placebo ( a "dummy" or "Fake" pill that is used to compare the actual drug)?
- Why do doctors believe this treatment may work?
- How will the study keep my name and records private?
- Will I have to stop taking any medication that I'm taking now?

### Risks and Benefits

- Does the treatment have any known side effects?
- Are there any other risks?
- How may I be helped by the new treatment?
- What other options for treatment do I have?
- How do the pros and cons of my other options compare with those of the study?

## QUESTIONS TO ASK YOURSELF

### Facts about the treatment and study

- How long will the trial last?
- How often will I need to come to the clinic?
- How many times a day will I need to take the drug?
- What other things will I need to do?
- How is the drug given - as a pill, in a shot, or in another way?
- What tests will I need to take?
- Will I be able to see all my test results?
- Who will treat me in the study?
- Will a social worker (or other trained staff) provide support and help me deal with problems?
- Will I see the same doctor or nurse each time?
- If I have a private doctor, can I keep seeing him/her?
- Where will I be treated after the study?
- If I take a drug that helps me, can I keep taking it after the study is over?

### Costs

- What costs will be covered by the trial?
- What other costs can I expect? Is there help available for these costs?
- Does insurance usually cover the costs that the study does not pick up?

# AIDS RESEARCH CONSORTIUM OF ATLANTA (ARCA)

(404) 876-2317

*"Working together to find a cure..."*

The AIDS Research Consortium of Atlanta, Inc. is a community based nonprofit organization founded in 1988 by physicians who treat patients with HIV disease. ARCA provides not only supervised clinical trials but also community presentations to update people with HIV on current and upcoming clinical trials.

In addition, ARCA offers an outreach program, providing treatment education to people who have traditionally been left out of clinical trials: women, people of color and substance abusers. These groups, historically, have not had easy access to either information or available services.

AIDS is everyone's problem, and ARCA prides itself on being a non discriminatory organization created to represent all infected patients in the Atlanta community.

**Mission**

To conduct clinical trials of new therapies for patients with HIV disease in order to ultimately find a CURE, and to create access for all Atlanta patients by offering clinical trials in their primary care setting.

**Who are the members of ARCA ?**

ARCA is a coalition of physicians from private, public, and academic medicine, nurses, physician assistants, pharmacists, health planners, epidemiologists, psychologists, educators, patients, and a professional staff who represent over 5,000 HIV infected individuals.

**Why Is there a need for a community-based research organization In Atlanta?**

The current backlog of clinical drug testing is a major threat to continued progress in efforts to fight AIDS. Community-based research organizations serve as a significant alternative to speed up the pace of AIDS research, while creating access to promising experimental therapies for people with HIV disease.

As the number of new AIDS cases in metro Atlanta continues to grow the need for local access to treatment and clinical trials increases substantially.

**Who funds ARCA?**

Programs are supported by government grants, pharmaceutical companies, private foundations, corporations, personal donations and volunteer help.

**How does ARCA work?**

Through relationships with the Grady Infectious Disease Program, the Veterans Administration Medical Center, Southside Healthcare Inc., and over 35 private practitioners, ARCA offers drug therapies, medical exams, laboratory tests and treatment education at no cost to patients. In return, ARCA gathers information on the effects that new therapies have on patients with HIV disease. Patients may be enrolled through the office or clinic of any ARCA member physician.

ARCA also sponsors monthly membership meetings that are open to the public. These forums serve to increase the availability of treatment information for both patients and their physicians and to ultimately improve the standard and quality of care in Atlanta.

# CLINICAL TRIAL REFERENCES 2

## NATIONAL

- AmFAR Treatment Directory
  (To obtain a copy: 1-212-682-7440)

- AIDS Clinical Trials Information Service
  1-800-Trials-A (1-800-874-2572)

- NIH sponsored trials in Bethesda, MD
  1-800-AIDS-NIH (1-800-243-7644)

- University of Alabama at Birmingham, 1917 Research Clinic
  (1-205-934-3690 or 1-800-822-8816, ask for 1917 Research Clinic)

## ATLANTA

- AIDS Research Consortium of Atlanta, ARCA
  (404-876-2317)

- AIDS Survival Project Treatment Resource Library
  (404-874-7926, ask for the Treatment Resource Specialist)

- Grady Infectious Disease Program
  (404-616-2440)

- West Paces Clinical Research
  (404) 350-5714

- VA Medical Center
  (404-321-6111, Ext. 7748)

## MISCELLANEOUS

- **Treatment Publications:**

*BETA*
*AIDS Treatment News*
*Treatment Issues*
*Notes from the Underground*
(all the above are available in AIDS Survival Project's Treatment Resource Center)

# FOOTNOTES

1. by Robert Rockwell, M.D. 1995

2. Compiled by David L. Wagner, J.D.

This section revised by R. Dunning Jr., R.N., M.N., C.S., May 1994

Updated by Alicia A. Culver, 26 February 1996

We Need:

# NOTES

- → Better protease / reverse transcriptase section.
- → Clean works demo
- → transmission - how HIV works
- → Graphics, tables, dingbats, fonts
- → Health care
- → Nutrition
- → living will, durable power of attorney
- → time keeper!!
- → Recommended reading
- → Nat'l Hotline sheet
- → Benefits (SSI, SSDI, etc.) Medicare, Ins. continuation
- → Poems, positive readings
- → handling stress
- → Immune enhancement
- → footnotes! use newsletters, mags, fact sheets, journals - book
- → name tags
- → Key contacts
- → Political - elective officials

# COMPLEMENTARY & ALTERNATIVE THERAPIES

**In addition to the articles in this section, please see Appendix B,**

**AIDS Treatment Initiative's**
**Complementary & Alternative Treatments and Therapies Guide.**

# EVALUATING ALTERNATIVE TREATMENTS [1]

Many individuals with HIV use some form of alternative or complementary medicine. It is extremely difficult to sift through all the various treatment alternatives available and evaluate which ones are truly valid and which are outright fraud. The following is a list of guidelines to help you in this process. It is important to look at a number of these factors to get an overall picture.

**Look for studies published in peer-reviewed medical journals.**

It is a myth that studies of alternative medicine are not published in reputable medical journals. If the studies are credible, they are published. AIDS Survival Project'sTreatment Resource Center has many of these studies on file. Because alternative medicines take a long time to reach the clinical trial stage, many of the published reports are on *in vitro* studies, meaning the testing was in a laboratory setting (i.e. test tube), not in people. Although in vitro studies are limited, since only a small number of them will have the same effects in people, they still are of value. If something works against HIV in vitro, there is reasonable scientific data to suggest its possible benefit in humans. In vitro studies are not extremely costly, nor do they take a great deal of time, so there is no legitimate reason not to do them. Do not blindly accept the promoter's statements that studies have been published in reputable journals, demand copies of those studies. Just because studies have been published does not mean the results were favorable. For example both phase I and II studies have been published on ozone therapy, however the results did not show any benefits to the individuals.

**Be wary of anecdotal reports.**

Personal testimonies of benefits are often the only "evidence" promoters use to substantiate their claims. Take, for example, the following scenario: a man we'll call Bob works full-time in a stressful job he dislikes. In addition, he has recently ended a long-term relationship and had a horrible fight with his mother. He has symptoms of fatigue, loss of appetite, dry skin, and depression. He reads an ad in the local community paper about a miracle cure in the Bahamas for $5,000. He decides to go and takes a leave of absence from his job. For three weeks Bob goes to an obscure clinic for an hour each day to receive his "miracle infusion" and does nothing else but relax on the beach watching sailboats. Well, after about a week, Bob miraculously begins to feel more energetic, his appetite returns, and he feels great. At the end of the treatment, he discovers his CD4 count has doubled. Bob feels eternally grateful to the "doctor" and writes a statement praising this miracle treatment, which is then given to other prospective clients. However, other prospective clients don't receive a copy of the letter Bob wrote three months later demanding a refund because his symptoms have returned and his CD4 count has dropped after he returned to his job and other stresses in his life.

Numerous clinical trials have proven the "placebo effect" is a very real phenomenon. Individuals who believe they are receiving a toxic drug in a trial often have side effects. For example, in the early AZT trials, many individuals receiving a placebo ("dummy" pill) had symptoms of nausea and vomiting as well as signs of anemia. The reverse is also true: individuals who believe they are receiving a drug that will benefit them have also shown temporary symptomatic improvement as well as increases in CD4 counts. The mind is a very powerful tool. Unfortunately, the "placebo effect" is only temporary.

**Consult with many unbiased sources before making a decision.**

The person selling the treatment is not an objective source of information because they stand to gain from your decision. Talk with informed individuals who are unbiased, like local treatment information organizations (such as AIDS Survival Project). Often individuals hear about new treatments from their friends who are trying them. Although there is usually no doubt that friends are truly sincere in their beliefs, they may be experiencing a "placebo effect" and can not really be considered unbiased sources.

**Demand to know what the treatment actually is.**

Many of the fraudulent treatments in the community are "secret" compounds. The promoters claim they can't reveal what is in them because the medical establishment will steal it. This is an unfounded excuse. Patents are easy to obtain and don't require a lot of time or money. It's your body and you have the right to know what you are going to put in it. There are actually "secret" compounds out there that are no more than mothballs and water or kreasote (the black tar residue on railroad pilings).

**Question the price of the treatment.**

Many of the standard drugs used for treating HIV and related opportunistic infections are overpriced. Drug companies often cite the high cost of drug development and research as the reason for the high price. Although this excuse is not 100% acceptable, there is some validity to it. What excuse does the promoter of a $3,000 cure give you? Chances are the compound has not been through extensive, costly development or in vitro studies.

**If the treatment is being touted as a cure demand proof.**

A testimonial from Bob stating he went from HIV positive to HIV negative is not proof. Insist on copies of Bob's Elisa *and* Western Blot tests both before and after treatment, then take these copies to your physician for verification.

**If it is necessary to travel to a foreign country for the treatment, question why.**

Travel to other countries can, in and of itself, be bad for your health for numerous reasons. You will be exposed to bacteria and other microorganisms that your body is not accustomed to, breathing recycled air during a long airplane ride can lead to respiratory infections, and the medical care in the foreign country may be substandard. If the treatment is legitimate, there is no reason you should not be able to get it here. Treatments which seem promising and are approved in other countries can be imported either on an individual basis or through a buyer's club (in Atlanta, check with AIDS Treatment Initiatives). Also, if the supposed "cure" really worked, that clinic would most likely be filled with local people and have long waiting lists.

**Interview the promoter.**

What degrees do they have and from where? If they claim to have a Ph.D. in microbiology from Harvard, check it out. A few dollars in phone calls and postage could save you thousands. Where did they work before they developed this treatment? What papers have they published? What achievements in medical research have they made? Is the promoter willing to answer all your questions, or does he skirt around them? Ask for a copy of their curriculum vitae (resume) which any reputable practitioner should have.

**Be wary of treatments which claim to cure multiple illnesses.**

A standard sign of fraud is the claim that a treatment cures both cancer and AIDS. AIDS and cancer are totally different diseases and it is unrealistically optimistic to believe one drug could "cure" both diseases. Many of the charlatans selling cures for AIDS were in business long before the AIDS pandemic, selling their same scams to people with cancer.

**Read any literature you are given carefully.**

Often the literature will contain only unsubstantiated claims of miraculous effects. Occasionally the literature will contain limited laboratory data of a few patients such as CD4 counts for patient #6, patient #32, and patient #73. What happened to the other 70 patients? If you want help analyzing the literature, take it to your physician or the Treatment Resource Specialist at AIDS Survival Project. Remember, anybody can write anything they want to, it doesn't mean it's the truth.

**If you must stop other treatments for this treatment to be effective, demand to know why.**

Many drugs interact adversely (causing side effects) with some other drugs, but very few (if any) compounds adversely interact with all drugs. Insist on reviewing drug interaction studies. For a researcher to say that a compound adversely interacts with another drug, it must have been studied, at least in vitro if not in humans. For example, some drugs have the same side effects and should not be taken together. Other drugs may compete for the same receptor sites, such as AZT and d4T, thereby decreasing the effects of both drugs. A broad claim such as "other chemicals will interfere with the natural balance of compound X" is not good enough. Discontinuing some medical therapies, such as PCP prophylaxis, can be extremely risky and should not be done without substantial proof that it is absolutely necessary.

**Look closely at studies performed in third would countries.**

Third world countries usually do not have the financial resources nor standardized, reliable laboratory equipment necessary to conduct a valid trial. A CD4 count done in an underdeveloped country would probably not yield the same results as one done in the United States, even if the same blood sample were used. The usual scenario is a wealthy entrepreneur from a developed country will set up trials in an underdeveloped country because the standards are much lower and it is easier to make false claims. Usually the studies are no more than uncontrolled treatment observations. As well, the very presence of a clinical trial in individuals with substandard living situations, and following these people with regular medical checkups, seeing that they have adequate nutrition, etc., may in itself cause the disappearance of signs and symptoms but have nothing to do with the effect of a drug.

You are ultimately responsible for what treatments you choose and this responsibility should not be taken lightly. Arm yourself with knowledge, patience, and never abandon your common sense. There are a lot of people out there who care a lot less about your health than they do their pocketbooks, and it is up to you to put them out of business by being a cautious, informed consumer.

# STEPPING OFF THE BEATEN PATH, 2

As a greater number of people with HIV realize the need to relieve stress and improve their quality of life, they find themselves taking that walk in the woods to explore complementary therapies—often Eastern techniques for which effectiveness is not clinically proven. Especially among people with HIV, complementary therapies are becoming increasingly popular. In fact, every year Americans as a whole spend approximately $14 billion on this type of treatment, and a report from the Ninth International Conference on AIDS shows use by as many as 86% of people with HIV (PO-2174). Other reports confirm this popularity.

**The road more traveled**

With the increased attention on complementary therapies, some may feel that they have become trendy, or that patients who use them are desperate, ignorant people who make hasty decisions. A 1991 study by Bonnie O'Connor of the University of Pennsylvania, however, found the opposite: People with HIV tend to evaluate therapies in a systematic fashion and base decisions on a large amount of personal research and evaluation of each treatment's rationale. A study presented in Berlin on the use of non-prescribed medication by people with HIV reported that 32% of people with HIV got their information on complementary therapies from their peers, 13% from scientific literature and literature for the lay person, and 6% from complementary practitioners (PO-2174). They also find resources in the newsletters of community-based AIDS organizations (such as *Survival News* from AIDS Survival Project), holistic health groups, and buyers clubs (like AIDS Treatment Initiatives). O'Connor and Dr. Don Abrams, in a separate study published in *AIDS*, drew these conclusions about persons with HIV who use complementary treatments: they are more likely to be well-educated and have higher socioeconomic status; they often belong to communities where information about these treatments is widely circulated; many belong to the baby boom generation, a group known to challenge authority and assume active responsibility in making decisions; and, they are more likely to use complementary therapies early in their disease, not when they are terminally ill.

**Walking the line**

Because complementary therapies are unregulated, one concern of persons with HIV is identifying quackery—practices more interested in making money than healing bodies. Here are a few pointers to help evaluate practitioners and their claims:

- Be wary of "cures" and claims of patients becoming HIV negative.
- Beware of practitioners who try to cut you off from your usual health care providers or who want you to give up other therapies.
- Beware of anyone who explains things in a manner either overly simplistic or complex, or refuses to reveal the formula of the therapies they use.
- Do not rely on a single source of information about any treatment.
- Be suspicious of high-priced treatments.

A good resource to find honest practitioners is Oriental medicine schools. Another resource is professional organizations, such as the International Foundation for Homeopathy at (206) 324-8230. People interested in these kinds of therapies should select a regular physician with whom they feel comfortable disclosing their experience with unconventional treatments. When used responsibly, complementary therapies can be useful tools for the management of HIV disease.

# THE BEST OF BOTH WORLDS 3

## COORDINATING ALTERNATIVE AND TRADITIONAL THERAPIES

Some examples of widely known complementary therapies include acupuncture, chiropractic, hypnotherapy, herbal medicine, homeopathy, naturopathy, biofeedback, and megadose vitamins.

Working with your physician to coordinate your general medical care and your complementary HIV therapies can be challenging. Many physicians have a difficult time accepting HIV treatments that are not grounded in clinically controlled, scientific evidence. Many patients have a difficult time accepting only FDA-approved therapies. Usually a compromise can be reached.

### Educating yourself

Addressing two important issues will aid you in building a better understanding with your physician about treatment choices:

- Educate yourself about HIV terms and treatment strategies. In order to effectively communicate with your physician about your ideas on HIV treatments, you need a firm grasp of the basics and you need to keep up-to-date on new developments. Subscribing to a few HIV treatment newsletters is a good idea or stop the Treatment Resource Center at AIDS Survival Project for copies. Remember that most physicians, even those with heavy HIV case loads, cannot keep track of every development in HIV treatments.
- Learn to evaluate the range of therapies that are not FDA-approved. Be skeptical of “miraculous cures” based on little evidence. Is the treatment based on controlled trials or is the “evidence” the personal experiences of only a few people? Are there high fees for the treatment? Are there claims of support from obscure institutions or journals?

The Reader’s Guide to Alternative Health Methods, published by the American Medical Association, is a directory that examines alternative diet, nutrition, and healing systems from the perspective of U.S.-organized medicine. It includes resource lists of proponents and opponents of many complementary treatments. To order, call (312) 464-5000 ext. 2035.

### Negotiating your relationship

Once you have educated yourself on treatment issues, try to negotiate an arrangement with your physician that suits both of you:

- Clarify the role your physician plays in your health care. This helps both of you understand the type of partnership you want. For instance, some patients look to their physician to control health care delivery. Other patients seek a collaborative arrangement between patient and physician. The more you learn about HIV treatments, the more comfortable you will feel taking a more active role in your health care. As your health changes, don’t be afraid to redefine this role.
- Schedule regular monitoring of your health through lab tests and examinations from your physician. Carefully weigh any advice or warnings he or she may offer, even if you have differing treatment strategies.
- Your physician has the right to refuse to endorse or prescribe a complementary or experimental HIV treatment; you have the right to a second opinion. The wide array of therapies and the treatment uncertainties concerning HIV infection necessitate that physicians treating people with HIV have a more flexible and individualized approach than usual.

**Where to look**

Where do you begin to look for a physician who will be more open-minded to complementary HIV therapies? Ask your acupuncturist, massage therapist, chiropractor, or herbalist. He or she may be able to refer you to a primary care physician supportive of complementary therapies. Health food stores and drug stores also may provide referrals.

Many cities have alternative treatment centers and buyers clubs that specialize in delivery of complementary health services and experimental HIV treatments. You can also get a referral from AIDS Survival Project.

The American Holistic Medical Association (AHMA) offers a list of physicians who incorporate holistic medical practices into their treatment style. For a complete listing of physicians in three states of your choice, send $5.00 to the AHMA, 4101 Lake Boone Trail, Suite 201, Raleigh, NC 27607.

# HEALTH WITH A CHINESE TWIST[4]

In broken English (which I've touched up and condensed considerably in the quotes that follow), my Chinese friend explained to me why we Americans aren't very healthy despite the billions we spend on health. "The problem," he said, "is your approach. You think you can become healthy merely by fighting being sick, but that's not the way life works."

"What do you mean?" I said.

He replied, "Does fighting bad habits create good ones? Does fighting ugliness create beauty? Does fighting war create peace? Obviously not. And fighting illness doesn't create health."

I began to see his point. We spend those billions of dollars studying diseases, which we then take on as if they were enemies in a war. The Chinese, by tradition, walk a more peaceful path. They study health, and seek merely to create it. They don't see the body under siege, nor do they adopt a warlike state of mind. They understand that fighting illness and creating health are two entirely different activities. And in the long run, fighting illness doesn't work.

Why? Because there's a rule of life that says we can't create what we want by opposing what we've got. The spirit of opposition is not a creative spirit. Acts of opposition are not creative acts. The goal of healing is not to oppose, which comes from fear, but to create, which comes from hope.

And creating health, my Chinese friend taught me, is a matter of balancing the body. Where balance exists, ill health cannot exist. So we don't become healthy by naming diseases, or by worrying about them, or by battling against them, or by trying to make them go away, but by creating health and balance in their place.

# COMPLEMENTARY THERAPIES USED IN HIV 5

## ENERGY BOOSTERS

*Consider the cause - more sleep and more peace*

- **B Vitamins** (nasal, oral or tablet)
- **Siberian Ginseng.**
- **Gotu Kola**
- **Suma** ("Brazilian Ginseng")
- **Green foods** (especially Klammath Falls Blue Green Algae. Contains Sulfolipids which are anti-infective.)
- **Nutritional support exercise.**
- **An immune modulator**

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## ANTIVIRALS

- **Compound Q:** More toxic.
- **Glycyrrhizin:** (Licorice Root) Causes cardiac stimulation
- **Hypericen:** (St. John's Wart) Some toxicities seen, is no longer recommended, causes increased liver enzymes.
- **Curcumin:** (Turmeric Powder)
- **NAC:** (available in capsule and effervescent form). Consider if having weight loss or diarrhea. Good for wasting. May help balance sensitivity to Bactrim. You can use up to 2000mg per day. It can cause Yeast problems in high doses, recommended dose: 600 BID with immune modulators
- **Silymarin or Milk Thistle:** 200mg. Excellent as a Liver protection.
- **COQ10:** Broccoli is a good source.
- **Ozone:** Best used as a bath. Bathe in lpt. 35% H202 per bath. Soak for 20 min.
- **Trental** (prescription drug): Lowers TNF (Tumor Necrosis Factor)
- **Vitamin C:** In conjunction with NAC has antiviral properties. Use Ester form or buffered form.
- **Zovirax** (prescription drug): 800mg taken 3x daily with AZT, helps keep down overgrowth of other viruses, particularly Herpes.

## IMMUNE MODULATORS

- **Carrisyn**(Acemannan): From the Aloe plant.
- **Oral Interferon:** Viroterm Immulin
- **PCM 4:** (Thymuril and Siberian Ginseng) Spleen peptide stimulates Thymus gland which is responsible for T cell production.
- **Resist/Enhance:** Chinese herbal combination developed especially for HIV.
- **Tagamet- Cimetadine** Available with Rx only.
- **IL2** (Interleukin 2): Very controversial. Clinical trials are being done through ARCA and the NIH. Must be highly supervised and the therapy has many side effects. Seems to be very hard on people with 200 T cells or less, without proven clinical benefit. Research is ongoing to measure longer term effects. Those with higher T-cells (300 or more) who began treatment with IL2 experience significant increases in T-cells, but this seems to be temporary. **Must** be taken with antiretrovials.

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## NATURAL ANTIBIOTICS

- **Echinacea:** May increase TNF pulse therapy. Use liquid extract if possible.
- **Garlic:** Good for digestion, use up to 2 to 3 times daily. Not good during wasting, increases heat in spleen area.
- **Golden Seal:** Good for skin sores.
- **Grapefruit Seed extract :** Excellent with Thsylyn for liver protection and parasites in Herbal Maxilife.

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## DIGESTIVE AIDS

- **Digestive Enzymes:** Wobenzyme, adult form. Not Ph Dep., plant type best.
- **Chlorella, Chlorophyll:** Intestinal cleanser.
- **Acidophilus:** Competes for binding sites on intestinal walls. Inhibits the binding of pathogenic bacteria. Requires refrigeration.

## FOR YEAST, THRUSH

- **Aqua Flora:** liquid / homeopathic
- **Pau d'arco herb**
- **Verdesol:** New
- **Consider a yeast free diet:** Body Ecology Diet / Donna Gates 266-1366

## FOR KAPOSI'S SARCOMA (KS)

- **Shark cartilage**
- **Bloodroot herb**
- **Pycnogenol:** 1mg per lb. of body weight in divided doses

## NEUROPATHIES

- **Peptide T:** Neural messenger, intranasal, 2mg TID
- **Cayenne foot soaks:**
- **B vitamins:**
- **Elavil:** Prescription drug
- **Massage / reflexology**

## OTHER HELPFUL HERBS

**Red Clover Combination** (Nature's Way): Blood cleanser

**Ginkgo biloba:** Increases circulation and memory. Contains Flavonoids and Quercetin good antioxidants. May be good for dementia along with B12. Contains Terpenes which increases blood flow. 40mg / TID.

**Essential Fatty Acids:** EPO, Borage Oil, Flax Oil, PGE 1 - anti inflammatory and antiviral, GLA Omega 6, EPA - Omega 3 good for viral infections, 500mg / QD.

**Kombucha Mushroom:** Also known as ancient Manchurian Tea Fungus: Fermentation process: conversion of black tea + sugar + mushroom, glucuronic acid (produced by the liver to detoxify and bind environmental and metabolic toxins) and lactic acid + B vitamins. Dose: 4OZ./3X daily. Local contact: Dorothy Dimpff 432-2368

**Essiac Tea:** Anticancer combination of 4 herbs developed in Canada. Available in tea form or tincture. You can also buy individual herbs.

**Colloidal Silver:** A general anti-infective.

**Maitake Mushroom:** Contains the polysaccharide glucan which is orally effective. Found to be clinically effective in vetro in protecting helper T cells from HIV destruction. Trials are being held at NIH. Also effective against KS.

# RECOMMENDED READING [6]

Staying Healthy with HIV
by David Baker & Richard Copeland
$10 at AIDS Treatment Initiatives or Mid-Towne Medicine Center

Immune Power
by John Kaiser

Treating AIDS with Chinese Medicine
by Mary Kay Ryan & Arthur Shattuck

AIDS Control Diet
by Mark Konlee

Holistic Protocol for the Immune System
by Scott Gregory

Body Ecology Diet
by Donna Gates

# SOME HOLISTIC THERAPIES

There are numerous alternative therapies which can be used to help strengthen the immune system. Therapeutic Massage, Chiropractic, Osteopathy, Homeopathy and Acupuncture are but a few.

**Therapeutic Massage** is known to alleviate pain and stress, increase circulation, speed healing, activate secretions, and help remove toxins from the lymphatic system. It can relax or energize the body, reduce muscle spasms and calm the mind. Some massage technicians have effectively helped to heal a wide variety of serious conditions. Examples of different therapeutic massage techniques available are: Aston Patterning, Shiatus, Acupressure, Touch for Health, Therapeutic touch, St. John's Neuromuscular Pain therapy, Hellerwork, Rolfing, Swedish Massage, Tui Na, and Polarity therapy.

**Chiropractic** involves the manipulation and adjustment of the spinal column. It works by stimulating the body's own resources to contribute to a variety of functional and musculo-skeletal disorders. Clinical studies have shown that chiopractic helps stimulate the body's immune system.

**Osteopathy** is a system of health care which recognizes that the self-healing, self-regulating ability of the body depends on various factors, including a favorable environment, both internal and external, adequate nutrition and normal structural integrity. It emphasizes the importance of techniques to detect and correct faulty structure and function. Another technique used is cranial manipulation, originally developed especially for infants injured during childbirth.

**Homeopathy** is a system of medicine that stimulates the individual to recuperate and cure him/her-self. Homeopathy does not use drugs or any artificial methods. Homeopathic remedies are based on ancient principles, dating back to India's Ayurvedic medicine and Greece's Hippocrates. In the late 18th century, Samuel Hahnemann, a German chemist and physician, began to reverify and formulate these principles. homeopathy is based on three principles: (1) the Law of Similars; (2) the Law of Proving; (3) the Law of Potentization. See the book by Anderson, M.D., Buegel, M.D. and Chernin, M.D., called Homeopathic Remedies for physicians, Laymen and Therapists, published by Himalayan International Institute, homesdale, Pennsylvania. To locate a homeopath in your area, call the Homeopathic Educational Service, 2124 Kittredge St., Berkeley, CA 94704; (510) 649-0294, or the National Center for Homeopathy, 801 N. Fairfax, #306, Alexandria, VA 22314; (703) 5a48-7790.

**Acupuncture** is an ancient Chinese system of needling various parts of the body to stimulate the body's own self-healing energy. Also used in conjunction with needling are herbs, lifestyle management, nutrition, meditation, Tai-Chi exercises, and Qi-Gong breathing exercises. Burning moxa (the herb Artemesia vulgaris) close to specific points or areas, to energize them, is also practiced.

**The following list includes other natural life-saving health practices:**

- ☛ Natural foods and supplementation therapy
- ☛ Catalytic vitamins
- ☛ Herbal therapy
- ☛ Lymphatic cleansing
- ☛ Ayurvedic medicine
- ☛ Ozone therapy
- ☛ Color and sound therapy
- ☛ Electro-magnetic resonance therapy
- ☛ Intestinal cleansing and implantation
- ☛ Hydrotherapy
- ☛ Sauna
- ☛ Fever, artifically induced
- ☛ Dry brush massage
- ☛ Exercise
- ☛ Fresh air
- ☛ Adequate sleep / rest
- ☛ Sunlight therapy
- ☛ Creative visualization
- ☛ Meditation and prayer
- ☛ Aromatherapy

# MORE THAN MEDICINE ,

Many people facing life-threatening diseases use a variety of treatments and therapies to support the medicines and care prescribed by their physicians. Use of these therapies can be part of a holistic approach to health care for the whole person: body, mind and spirit.

When evaluating these therapies, it may be helpful to group your choices under two broad headings: complementary and alternative.

Complementary therapies:
used along with your physician's prescribed treatments.
Alternative therapies:
used instead of treatments usually prescribed for a medical condition.

## COMPLEMENTARY THERAPIES

Complementary therapies are compatible with medicines or therapies prescribed by a physician to fight viruses, bacteria, fungal infections, and other disorders related to HIV. Complementary therapies can help improve the user's health, mental attitude, and sense of self-control.

Acupuncture, chiropractic manipulations, massage, and yoga are some common complementary therapies. Others include acupressure, Rolfing, regulated doses of vitamins and minerals, intake of herbs or other organic substances, and diet changes such as reduction in sugar or increases in daily intake of vegetables and high-fiber foods.

Additional complementary techniques include those which help redirect thoughts, attitudes and emotions: meditation, visualization, self-affirmations, guided imagery, and biofeedback. Programs of stress-reduction, stretching, aerobics, Tai Chi, yoga, and exercise also contribute to a well-rounded approach to better health. Another complementary service gaining recognition is social support provided by free or low-cost self-help groups.

## ALTERNATIVE THERAPIES

For a wide variety of reasons, some people choose alternatives to government-recommended drugs that attack HIV and treat or prevent its related infections.

Patients may turn to alternatives when they fear or mistrust conventional treatments, or when conventional treatments lose their effect, have no effect, or have intolerable side effects. Some individuals want only natural or organic treatments. Still others put their total trust in spiritual, or mental healing.

Further motivations toward alternative therapies for HIV include mistrust of the medical establishment, bias against particular drugs or manufacturers, lack of insurance or money, or doubts about the connection between HIV and deterioration of the immune system.

The term "alternative treatment" is also used to contrast medicinal approaches from China and other "Eastern" countries with those of 20th century "Western" technology. Ancient treatments from native North and South Americans tribes may also be described as alternative treatments.

There are many countries where money is not available to pay for diagnostic tests, drugs, hospitalization or surgery. In these regions, treatments that are indigenous (native) to the country may be the only ones available. International researchers are studying these indigenous treatments to determine how helpful they might be in the worldwide fight against HIV and its infections.

**Summary**

Anyone dealing with HIV disease should seek objective evidence for the wide variety of treatment options available to them — from acupuncture to AZT. If you choose to use complementary or alternative therapies, inform your primary physician and ask to be monitored regularly for positive or negative results. If your physician refuses to cooperate and you're determined to continue the therapy, seek another physician who will monitor your overall health and physical signs while you use non-prescribed therapies.

A holistic approach to HIV disease includes positive choices about what you eat and drink, your thought and emotional patterns, the ways you deal with physical stress, and your social and support networks. These all can affect the impact of HIV on your life. A holistic approach also includes basic steps like avoiding nicotine, alcohol or substance abuse, and getting sufficient nourishment, rest and exercise.

# BASIC GUIDELINES FOR STRENGTHENING THE IMMUNE SYSTEM

## AVOID

- Meat, eggs, poultry, dairy foods, candy, soft drinks and foods with concentrated sweeteners (sugar, honey, maple syrup, etc.), oily foods, coffee, alcohol, chemicalized foods, antibiotics and recreational drugs.
- Overexposure to direct sunlight
- Chaotic eating and living habits
- Looking to blame outside forces for your unhappiness/sickness
- Dependence on entertainment for enjoyment of life
- News and people promoting doom and gloom
- Overwork, exhaustion
- Excessive exercise
- Stress
- Cigarette smoking

## EMPHASIZE

- Whole grains, beans and bean products, leafy green vegetables, and other wholesome, natural foods
- Regular, moderate exercise known to benefit health: yoga, tai chi, walking, dancing, etc.
- Holistic therapies such as massage and acupuncture
- Meditation, relaxation techniques, prayer
- Self-enriching and creative activities
- Positive, supportive friends and groups
- Fresh air and sunlight
- Orderly life habits
- Good breathing habits
- Adequate rest and sleep

## REMOVE TOXINS

Be aware that everything you put into your body affects it in a positive or negative way. Show your body that you love and respect it. Start by eliminating as many toxins as possible including:

- Recreational drugs and stimulants
- Prescription drugs - only with the advice of a health care practitioner
- Industrial chemicals
- Infections and parasites
- Food additives and preservatives

## DIET & NUTRITION

***"Let Thy Food Be Thy Medicine and Thy Medicine Be Thy Food"*** **- Hippocrates**

Diet and Nutrition can greatly enhance your immunity and build resistance to infections. Improved daily eating habits reduce stress on the body and provide the basic building blocks for good health. Use your common sense.

- Eat a variety of fresh fruit, vegetables, fish & poultry. Balance your diet with ample whole grains such as brown rice, barley & oats.
- Restrict your intake of sugar, empty carbohydrates, milk products & foods containing yeast (especially for yeast infections).
- Consider such specific dietary/healing regimens as
  a) Macrobiotics
  b) Living foods
  c) Vegetarianism or modified vegetarian diet
- Consult a nutritionist or holistic practitioner when developing a diet & nutrition plan.

### ATTITUDE

Positive attitude is absolutely essential to your healing and can keep your immune system from shutting down in reaction to fear, anger and resentment.

- Read books, listen to tapes & participate in programs on attitudinal healing & spiritual or philosophical study.
- Help others.
- Become involved in support groups & develop positive, supportive friendships.
- Counseling & co-counseling. Consider such processes as deep body work, rebirthing, Reichian therapy & Bioenergetics, the AIDS Mastery, & hypnosis/past life regression as means of clearing out blocks to living fully.
- Live every moment with the zest of life.

### EXERCISE & BODYWORK

Be good to your body! Exercise strengthens support for your internal organs, improves digestion and increases nutrient and oxygen exchange in tissues and enhances immune function. Choose activities that you enjoy.

- aerobics such as walking, running & bicycling
- strengthening exercises such as yoga massage

### REST & RELAXATION

Stress lies at the root of disease. Develop active relaxation techniques which allow your body to heal itself.

- Deep relaxation
- Breathing exercises
- Plenty of rest, naps & sleep
- Meditation

### OTHER THERAPIES

These may involve some risk and do require additional education and consultation with a doctor or health care practitioner. Therapies receiving great attention today are:

- Vitamin/Mineral supplementation including Vitamin C, beta-carotene & Zinc & many others
- Foods with life enhancing, immune-building & antiviral properties including herbs, garlic, algae, Spirulina, shiitake mushrooms, wheat grass juice and many others
- Herbal therapy
- Acupuncture & Chinese medicine
- Homeopathic medicine

### SELF PROGRAMMING

The following techniques have been used successfully by many in their healing programs:

- Meditation
- Visualization
- Affirmations
- Self-hypnosis

# NON-TRADITIONAL THERAPIES [8]

We believe that AIDS is not a 100% fatal disease. We base this belief on our own personal experience because we have known people who have continued to live with AIDS for over a decade. People with AIDS (PWA's) learn to live with the condition by focusing on the here and now and living one day at a time. Their lives are vital and focused on the opportunities life continues to offer. We believe this attitude is essential to health and happiness.

Over the past 6 years we have both worked with many PWA's and HIV positive people, and we have known people who continue to live, with and without the use of common medical therapies. We are including quotations from PWA's and HIV positive people to assist the reader in exploring some of the issues involved in making decisions about non-traditional therapies.

Current medical belief is that HIV infection will most likely progress through the continuum to "full-blown AIDS." We have observed that some people continue to live no matter what the medical diagnosis is—HIV positive or AIDS—and that some practices enhance well being. We will explore these practices.

We are not suggesting that non-traditional therapies alone are enough. We do believe that they can be powerful additions to traditional therapies, an active way to participate in one's own treatment, and the vehicle to allow one to follow one's own intuition or inner voice. It is our experience that it is helpful to begin with what internally feels like a good move. Talking with the practitioner of the therapy and being alert to how the therapy process feels are ways of actively participating in one's own treatment. Questions that might be asked are: "Does this therapy seem to reach or communicate with a part of you that is at peace or feels whole? Does your participation in the process interest you? Does the practitioner listen to you?"

We have grouped the non-traditional therapies into three categories: physical, mental, and spiritual. Although these are, in a sense, artificial categories, we are using them as a way of talking about the component parts of a person. Actually, we believe that mind, body, and spirit are parts of a whole, a dynamic unity. We realize that not everyone agrees with us, but we suggest that there is something to be gained from viewing things in this way.

## PHYSICAL THERAPEUTICS

### Diet and Nutrition

Many people would never put inferior quality fuel in their cars. Yet when it comes to eating, the same people go for convenience rather than quality of food.

How one eats is as important as what one eats. A clean, quiet, and pleasant atmosphere provides a nourishing environment in which to receive one's food. The food we eat is digested and becomes our body, therefore, the circumstances of our ingestion are important to our health and well-being. Eating slowly, and especially chewing, fully prepares the food for maximum efficient digestion, including more surface area for the digestive process and comfortable peristalsis (digestion).

From our experience working with people who are HIV positive, we have outlined some general principles and suggestions about diet and nutrition.

1. Whole grains are beneficial to most people and can be eaten twice a day.

2. Both raw and steamed vegetables are also beneficial. Overcooked food and food treated with chemicals lose much of their nutritional value. Raw and cultured dairy products (yogurt, kefir, etc.) are suggested.

3. Minimal meat intake is usually best, and red meat should especially be avoided because of cholesterol considerations.
4. In avoiding meat, however, PWA's should be sure to include enough protein-rich foods in their diet. Some nutritionists believe up to 40 grams of protein per day benefits PWA's.
5. Elimination of all beverages containing caffeine is suggested.
6. Elimination of chocolate, sugar, white flour, and preservatives is recommended.
7. Avoidance of iced or very cold food is suggested. The digestion process is eased when foods are served at room temperature.

Stress affects the immune system, and stress-producing foods, a poor diet, over indulgence of alcohol and drugs, all have a price. In addition, alcohol and recreational drugs are now being thought of as co-factors in the progression from testing HIV positive to AIDS because they can weaken the immune system and thereby increase one's chances of opportunistic infections.

Suggested supplements to the diet are Vitamin C, garlic, zinc, calcium, and B vitamins. Vitamin C strengthens the body's general resistance to viruses and helps with elimination. Garlic is an antiviral. Because of its strong smell people often take the processed form (Kyolic). Zinc is an integral component of immune system functions. Calcium soothes the nerves. B vitamins aid in healing.

When changing your diet, it's important to keep a food diary. Keep track of what you eat, when you eat it, and the effects you feel that can be attributed to the food.

Edgar Cayce said that "What we think and what we eat make up what we are." Have nourishing thoughts as you eat nourishing food.

### Acupuncture

Acupuncture can be used in addition to Western medicine. It is the practice of placing needles under the skin at various points in the body in order to redirect the body's energy flow. Acupuncturists believe that illness and pain are caused by the blockage or imbalance of internal energies, and the purpose of treatment is to unblock or rebalance these energies.

"When I first tried acupuncture I couldn't believe I was sitting in a place where they were going to stick needles in me. To my surprise the needles are tapped under the skin without any experience of pain, as compared to the pain in receiving a shot of penicillin."

The thinking that goes along with Chinese medicine is that the person is whole—everything working together, mind, body and spirit. Western medicine thinks of a person in terms of systems, and there is a specialist for each bodily system.

"I've developed a relationship with the acupuncturist. She explains to me about health and that the body has the power to heal itself and acupuncture aids the body in that process. Acupuncture adds to my feeling whole and complete as a person. I think the best way I can take care of myself is by allowing myself to experience the best of both worlds, Western and Eastern medicine. This thinking challenges me to educate myself about my health needs and to make decisions about my own health care. I do this by collecting information, talking with my health care practitioners, praying about it, and following my inner voice, thus causing me to feel responsible for my health situation. This also does not allow me to play the victim while allowing me to experience and express my own power over myself."

## BODY WORK

"I feel at home again" is one comment that is made after some form of body work. It could be reiki, shiatsu massage, or Swedish massage (descriptions of each are found in the paragraphs below). What often happens is that people with health issues spend more time living "in their heads" than living in their entire bodies. Sometimes it appears that the body is the enemy or the "problem," and must be watched for symptoms. Another related issue is that some people with AIDS become less physical with others. Touching and being touched often serve as powerful stress reducers and pleasure creators. Being cared for by someone else and touched in a supportive way often increases a sense of well-being. Sometimes people with lesions begin to feel disgusted by their bodies. To experience someone touching them in a loving way may encourage self acceptance.

The quieting of the mind that happens during body work is often that much needed rest from thinking, "What should I be doing? Am I doing enough? What if?" etc.

Learning to do body work techniques on oneself is empowering. It also gives one something to pass on to another and is a way of making connections with others.

### Reiki

This is an Oriental term that means "universal life force energy." By holding his or her hands close to but not touching the receiver's body, the reiki practitioner is said to activate and balance the life force energy. The techniques focus on the contacting of the energy field or aura around the body. This therapy is used for mental distress, chronic and acute physical problems, and is thought to enhance the function of the lymph system.

### Shiatsu

This is a Japanese word meaning finger pressure. It is also called acupressure and is sometimes thought of as acupuncture without needles. Varying degrees of finger pressure are used to balance the life energy that flows through the body. After a shiatsu session people often report achieving a meditative, peaceful state. One optimal benefit is that shiatsu, like acupuncture, strengthens the lymph system.

### Swedish massage

This type of massage consists of manipulations and long strokes that soothe the peripheral nerves and skeletal muscles and enhance general circulation. It, too, is thought to enhance the lymph function. Swedish massage assists the body's healing process by stimulating the elimination of toxins and facilitating the nutrition of tissues as well as producing an overall state of deep relaxation.

We talk about these forms of body work as if they are separate and discrete. Actually, the same general effect may be produced by all.

### Exercise

Most of us know the joy and feeling of well-being that comes from exercise. We eat with more enthusiasm, sleep with more ease, and move with more elasticity and vigor. There are many forms of exercise and body movement. We have chosen to focus on the practice of **Hatha Yoga.** Hatha Yoga has been used for years in Asia as a way to develop and maintain a flexible body and to strengthen immunity. In contrast to gymnastic exercises, Hatha Yoga emphasizes smoothness of movement and ease of muscle stretching. It is helpful for releasing tensions, balancing the energy throughout the body, and increasing the flexibility of the spine.

The slow, connected movements of yoga emphasize the body as a total system. Doing this form of exercise properly enables one to feel connected, refreshed, and tranquil. Hatha Yoga is a way of physical training to prepare the mind and body for meditation.

## MENTAL THERAPEUTICS

### Talk Therapy

The scope of talk therapy is broad and includes individual counseling, psychotherapy, primal therapy, group therapy, as well as support groups, Twelve-Step programs, and so forth. We have consolidated aspects of many forms of talk therapy in order to show the benefits of speaking about one's own thoughts and feelings. One person's experience with talk therapy will illustrate this.

"In 1984, I went for a checkup because at that time there was a lot of talk about AIDS. Previously, I had been an IV drug user and into anonymous sex with numerous men, which meant that I was in a high-risk group for the virus. At that time I was diagnosed with thrush, a yeast infection of the mouth commonly found in people with the virus. From that time until I was diagnosed with AIDS in 1986, I lived with fear and anxiety about AIDS and I didn't talk much about it in hopes that it would just go away.

When I was diagnosed with AIDS I was relieved to find out that I wouldn't die immediately. Then I realized I had a choice: either I could learn how to live with AIDS or I could wait and die. I chose to live with the condition of AIDS. After choosing to live I found that I needed to educate myself about the virus and how it operates. I also read books such as *Love, Medicine and Miracles,* by Bernie Siegel; *The Anatomy of an Illness*, by Norman Cousins; and *You Can Heal Your Life,* by Louise Hay. These books opened my mind to how I might live with AIDS. I also began talking with others who had the same condition to learn how they were dealing with the virus. By talking with others I developed the attitude, if others can live and be happy with a life-threatening illness, so can I.

I spent most of my life emotionally isolated from people. After I found out that I had AIDS, I went to my therapy group and I started talking about how I was feeling and this began the end of my emotional isolation. Now I started to feel more alive than when I didn't have AIDS! Feelings of anger, rage, sorrow, fear, and anxiety were common when I was first aware of having the virus. Talking about these feelings, whether it be with a close friend, a therapist, in a group therapy situation, a support group or a Twelve-Step meeting, allowed me to feel better about myself. I also believe that holding onto these emotions and not expressing them can cause harm to the immune system, and expressing them and letting go of them can enhance it. Today, I am very interested in reading about and experiencing the effect that emotions and attitudes play in relation to our immune system.

As I mentioned before, anger was my first reaction to the diagnosis of having the virus. I began to learn how to express my anger in a constructive way. For me, this meant allowing myself to let the other members in the therapy group know how angry I was. This was probably one of the scariest things I've done. But I am here to say that I got through the experience and am a better person for it! Because I am in recovery from addiction, I attend Twelve-Step meetings for recovering addicts who are HIV positive or have AIDS. Here we all talk about how we are handling the diagnosis. One thing that I have observed is that people who are in Twelve-Step programs tend to be more accepting of their situations. I've noticed that when a member of the group becomes ill, he or she is surrounded by people while in the hospital. Opening up and talking to people about our experience allows us to be there for people and for others to be there for us.

When I was in the hospital with my first episode of PCP (pneumocystis carinii pneumonia). I had people in to visit every day. One of the things that touched me about this was that I wasn't alone and that I could really count on others to be there. This was not always the case in my life. I came from a place of addiction, back room bars, and bath houses. The only time that people communicated was to solicit drugs or sex. AIDS has given me the opportunity to begin to know who I am, my thoughts and feelings, and to begin to identify and explore these with others by using talk therapy."

## Spiritual Therapeutics

Concepts of God, religion, and spirituality are for many of us unpleasant, repressive associations from childhood. Such a perspective notwithstanding, there are other ideas about spirituality that can be tremendously supportive and even transforming. There are countless perspectives on spirit and spirituality, ranging from various organized religious practices to individual observances, and employ such techniques as meditation, prayer, chanting, and the use of crystals and affirmations. Two ideas, metaphysics and higher power, are developed here.

### Metaphysics

Metaphysicians believe that our thought is creative and powerful— what we think we attract to us. If our tendency is to think we are separate and alone, we will create those situations in our lives. It also follows that what we think, we can unthink. If we have created unpleasant conditions as a result of our thinking, we can reverse our situations by changing how and what we think.

Willis Kinnear's book *30-Day Mental Diet* recommends we pay attention to the kinds of thoughts we allow in and retain. He asserts that our thoughts often determine the functioning and the health of our physical bodies, as well as the state of our relationships with others, and the degree of success which we may be able to achieve.

### Higher Power

Believers in a higher power accept that a central force exists in the universe which guides them through life. This force has been given many names. The point is that belief in a higher power enables believers to act and feel in ways beyond what had earlier seemed possible to them. By merging with the universe and surrendering to a power greater than oneself the individual acknowledges that he or she can't control everything and that the results are in the hands of a higher power. For example, we may be frozen with fear and our conscious contact with a power greater than ourselves can help us move through our fear and thereby transform the fear into faith. Here is a story of how belief in a higher power works in the life of one PWA.

"I was raised Catholic and I believed that God was something outside of me. I was taught that I would be acceptable to God if I did certain things. Well, I never felt that I measured up to what the Church taught me. When I started to have feelings of homosexuality, I prayed that God would remove them. Well, they weren't removed; I got angry at God and set the idea of God on the shelf. I was ashamed and guilty for having these homosexual feelings. Also, the message I received from society about homosexuality was negative, allowing me to feel I wasn't worthy of love from a higher power.

A short while after I was diagnosed with AIDS I spoke to a person who had been asymptomatic for a couple of years. When I asked him to what he thought he owed his state of health, he told me that he did what his doctors told him to do, he ate well and exercised daily, and whatever was too much to handle he turned over to his higher power. He said he learned to contact that place inside of himself that was in touch with a power greater than himself alone. I knew what he was talking about; to me this means to follow my inner voice.

Coming to believe in a higher power helps me through the rough times. Recently, I have experienced severe headaches. This has been going on for about nine months. Because I have had AIDS for the past two years, having the headaches caused me a lot of anxiety and fear. You see, even though I have AIDS I still live a full and productive life. I have been sick twice. Once with PCP and the second time with a bacterial infection. Since my second bout of illness I have been free of infection and other symptoms. When I started to experience headaches I had tests done, including a spinal tap, and a CAT scan of the brain. Both were negative. I also went to an ear, nose and throat specialist, and had sinus x-rays. Then I was treated for sinus infections with antibiotics. As the headaches still persisted, I then tried acupuncture and I received some relief from the pain, although the problem still persisted in cycles. I then stopped all medications based on the idea that I could be having a reaction to AZT or Acyclovir, the two medications I take for my condition. I even went to an allergist and was tested for allergies. The allergist said I was allergic to dust, but that he would not treat me with immunotherapy because he didn't feel safe about stimulating my immune system. I have finally traced the cause of the headaches by noting that they occur every two weeks, persisting for about five to seven days, and then clear up. This coincides with the use of Pentamadine, an aerosol mist used to prevent PCP.

Belief in a higher power has helped me to continue looking for the cause of my physical pain. I didn't give up but I did surrender my attempt at controlling the situation. I asked my higher power to give me the courage to take the next step. During this time I continued to work at my job, socialize with my friends, play with my animals and complete course work at school. I know that if I didn't have a belief in a higher power I would have felt the headaches were too much to go through and I would have hoped to die. I went to a Christian Science practitioner and she told me that God's love is like the sun—it shines everywhere and I am the one who walks through life with an umbrella, shadowing God's love from me. I have a choice to stay in the shadow or receive the love.

Since my diagnosis of AIDS I have to deal with my feelings and thoughts about death and dying. I am afraid of the dying process more so than death itself. I have read books about death and dying so I might begin to gain a perspective on death. My understanding of death today is that it is not a matter of winning or losing, it just is."

## NEXT STEPS

Life is not a technique and the process of living is more than adding together some mind plus some body plus some spirit. Mind, body, and spirit cooperate. Just as the fingers and thumb together accomplish something more and something different from the actions of each member, so too do body, mind, and spirit. The connection of the body to the earth, the connection of the mind to larger thoughts, and the connection of the spirit to all that is, creates a universe within a universe. Krishnamurti wrote *Ku Are the World* in which he says, "In oneself lies the whole world, and if you know how to look and learn, then the door is there and the key is in your hand. Nobody on earth can give you either that key or the door to open, except yourself." Does this sound interesting to you?

We believe that techniques can help you learn about yourself and help you connect with others. We suggest that you work with others who support you. If that means organized religion, that's fine. If it means exploring new areas to you such as Christian Science or Science of Mind, then try that. Throughout the U.S. and Canada there are Twelve-Step groups for people in recovery from co-dependent relationships, drug addiction, alcohol addiction, compulsive sex addiction, food addiction, addiction to gambling, and emotional addiction.

If you are in an isolated area or an area where there is a lot of misunderstanding and fear about HIV infection and AIDS, you can start by doing reading that sounds promising.

People have experienced two roads with AIDS and HIV infection, acceptance or despair. Many people see it as a death sentence. If you follow that line of thinking, then simply being born can also be seen as a death sentence. AIDS and HIV infection can also be seen as an opportunity for growth. In this context, health and happiness are not produced by situations but they are produced by one's own mind. Through the process of meditation and visualization we can listen to and create new thoughts that could lead to a sense of wholeness and well-being.

One person with AIDS told us, "I can remember when I first heard the notion of alternative therapies. I thought and felt the whole thing was nonsense. I have since discovered that it's really important to keep an open mind. I went from feeling complete contempt for the mumbo-jumbo of alternative therapies to incorporating these same therapies in my daily life."

# AIDS TREATMENT INITIATIVES

### (FORMERLY THE ATLANTA BUYERS CLUB)

**providing access to alternative treatments for the HIV community.**

**Why a Buyers Club?**

In December, 1988, the Food and Drug Administration revised its rules on the importation of drugs for personal use, making it legal. This action recognized the failure of our medical system to respond adequately to the AIDS pandemic.

Even though our system was well-intentioned and diligent, it no longer worked with a disease as radical and fast moving as HIV.

The last landmark drug development in America was the Salk polio vaccine in the 1950's. By the late 1980's, an embarrassingly large stream of Americans were leaving the country seeking medical treatments.

The FDA had the integrity to recognize their failure and, to the shock of the medical establishment, made it easier for people to gain access to treatments from abroad.

As a result, buyers clubs emerged around the country to act as conduits for the flow of treatments. As part of this movement, AIDS Treatment Initiatives was formed in order to provide access to alternative treatments for the HIV community.

**Be Informed and Get Involved**

We believe that HIV infection is survivable through a combination of early preventive measures and aggressive treatment of opportunistic infections.

This philosophy is accompanied by the belief that people with HIV should become informed about and involved with their own program of treatment.

Treatment options must be made more affordable and easily available.

In addition, self-empowerment is a critical asset in pursuing an effective approach to treatment.

To this end, we are committed to helping our members obtain treatments that they believe will help in their battle against HIV.

**Take Charge of Your Health**

Assume a share of the responsibility for your own treatment by taking charge of your health.

We need to help our doctors, as they have helped us, with the risk and liability of this illness. The doctor/patient relationship is a partnership, not a dependency. By educating ourselves and our physicians about alternative treatments and access to them, we can better manage HIV infection.

**How AIDS Treatment Initiatives Operates**

Although we concentrate on providing alternative treatments for the Southeast, we will assist anyone. You can contact AIDS Treatment Initiatives at the address and phone numbers at the end of this article.

We are not medical professionals and cannot recommend any particular treatment/drug. We provide information on treatments we offer but make no claims for them. Monitoring, dosage and side effects should be discussed with your primary health care provider.

All information about AIDS Treatment Initiatives members is confidential. Transactions are recorded by a membership code assigned to you to insure your right to privacy.

**The Basic Message**

Be informed. Read everything you can to educate yourself, and your physician, about HIV.

Learn about your treatment options and take advantage of them. There is more to HIV than AZT and pentamidine. Take charge of your health.

Make your doctor aware of what treatments you are interested in. If you feel uncomfortable doing this with your physician, look for another.

While AIDS Treatment Initiatives does not endorse any treatment, we can assist you in obtaining alternative treatments and information about them.

*"One thing we do know for sure: there is indeed light shining at the end of the tunnel. Now, more than ever, the challenge is to use all that is at our command to hang on. We are very, very close, and some reputable sources believe we are already there for those who begin treatment sufficiently early."*

- Martin Delaney, Project Inform

For more information contact:
AIDS Treatment Initiatives
828 W. Peachtree Street
Atlanta, GA 30308
Telephone (404) 874-4845
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# FOOTNOTES

1 by Laury McKean, RN, Seattle Treatment
Education Project (STEP)

2 by Stephan Korsia
*Positively Aware.* Fall 1993
Stephan Korsia is former editor of *I Heard it Through the Grapevine*, a newsletter published by AIDS Project Los Angeles.

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8 Edited by
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# DISABILITY

# APPLYING FOR SOCIAL SECURITY DISABILITY 1

1. Contact the Social Security Administration (SSA) at 1-800-772-1213.

2. Identify yourself as a person with HIV/AIDS.

3. Notify them that you would like to apply for disability.

4. They should place you in contact with a local SSA office and counselor either by giving you the phone number and name of the person you should call or by telling you that someone will call you. This "appointment" with the local office should occur within two days. If not, you should follow up with the SSA at 1-800-772-1213.

5. You will get a case worker and be sent lots of long forms. Do not get discouraged! You must complete the forms to be considered. You may also be asked to undergo, at SSA's expense, a battery of interviews and simple tests as part of a vocational/rehabilitational assessment. Do not miss any appointments or deadlines for completion of forms. You will be asked to sign a release allowing SSA access to your medical files.

6. You may be eligible for two types of benefits — Supplemental Security Income (SSI) and/or Social Security Disability Income (SSDI). SSI is a program based on need. You are not eligible for SSI if your total financial resources (from bank accounts, IRAs/CDs, life insurance, property, etc.) total more than $2000 or if you earn more than $422 per month. In other words, it is for the truly needy.

SSDI is a benefit that you are entitled to because you are a worker. There are no income or resource guidelines, but you must have worked for at least five out of the last 10 years (during which time you paid Social Security taxes!). Your benefit amount will be based on your work history.

7. If you are eligible for SSI, you can expect a check as soon as you are determined to be disabled. You are also eligible for Medicaid if you are approved for SSI.

If you are eligible for SSDI, you can expect a check five months after the date you were determined to be disabled. For obvious reasons, it is to your benefit to be able to prove that your date of disability is well in the past so that upon approval of your disability claim, your five-month waiting period is over. Should you claim a date of disability in the past when filling out your SSA forms, it is best that there be a specific milestone or illness (that coincides with your date of disability) that can be substantiated through your medical records. It is also very important that you not work during this five-month period!

8. Checks from SSA come at the end of the month for which the benefit is being paid.

9. For persons with private disability insurance — it is typical for your disability benefit from your private insurer to be reduced by the amount of the SSA disability award. In other words, your total disability benefit won't change, you'll simply have both a private insurer and SSA "splitting" the payments.

# DISABILITY FOR PEOPLE WITH HIV, 2

## Background Information

Acquired Immunodeficiency Syndrome (AIDS) is characterized by the inability of the body's natural immunity to fight infection. It is caused by a retrovirus known as Human Immunodeficiency Virus, or HIV. Generally speaking, people with HIV infection fall into two broad categories:

1) those with symptomatic HIV infection, including AIDS; and

2) those with HIV infection but no symptoms.

Although thousands of people with HIV infection are receiving Social Security or Supplemental Security Income Disability benefits, there may be others who might be eligible for these benefits. Some may be eligible even if their condition improves or stabilizes enough for them to return to work.

## Highlights of the New Rules

In response to the many comments received about the proposed rules for evaluating HIV infection, the Social Security Administration (SSA) extensively revised the final rules compared to the previous rules. These revisions included general clarifications and addressed the many concerns raised regarding the equal evaluation of claims of women and children infected by HIV. The proposed final listings include:

- Diseases that have been considered AIDS-defining, e.g., pneumocystis carinii pneumonia.

- Manifestations of symptomatic HIV that have not been traditionally considered AIDS, such as diarrhea and cardiomyopathy.

- Several manifestations that affect women and girls, e.g., vulvovaginal candidiasis with extensive ulcerating lesions not responding to treatment.

- A way to evaluate other repeated manifestations by using functional criteria that may qualify an applicant for disability.

- Child-specific documentation rules and manifestations specific to children.

- Criteria for evaluation of growth disturbance in children with HIV infection.

## What Benefits Are You Eligible For?

Social Security pays disability benefits under two programs: Social Security Disability Insurance, sometimes called SSDI, and Supplemental Security Income, often called SSI. The medical requirements are the same for both programs, and your disability is determined by the same process. However, there are major differences in the nonmedical factors, which are detailed on the following pages.

## SOCIAL SECURITY DISABILITY INSURANCE BENEFITS

### The Nonmedical Rules of Eligibility

Here are examples of how people qualify for SSDI:

- Most people qualify for Social Security Disability by working, paying Social Security taxes, and in turn, earning "'credits" toward future benefits. The maximum number of credits you can earn each year is four. The number of credits you need to qualify for disability depends on your age when you become disabled. Nobody needs more then 40 credits and younger people can qualify with as few as six credits.

- Disabled children age 18 or older could be eligible for dependents benefits on the Social Security record of a parent who is getting retirement or disability benefits, or on the record of a parent who has died. (The disability must have started before age 22.)

- Children under the age of 18 qualify for dependents benefits on the record of a parent who is getting retirement or disability benefits, or on the record of a parent who has died, merely because they are under age 18.

For more information about Social Security Disability benefits, request the booklet, *Disability* (Publication No. 05-10029). The SSA number is 1-800-772-1213.

## HOW MUCH WILL YOUR BENEFITS BE?

How much your Social Security benefit will be depends on your earnings history. Generally, higher earnings translate into higher Social Security benefits. You can find out how much you will get by contacting Social Security by calling 1-800-772-1213 and asking for an estimate of your benefits. They will send a copy of form SSA-7004-SM that you can use to send for a free statement that contains a record of your earnings and an estimate of your benefits.

Besides checking your benefit, you can use this statement to verify that your earnings have been properly recorded in Social Security's files. It's important that you do this because any missing or unreported wages could lower your Social Security benefit or even prevent you from qualifying for disability benefits. Check carefully if you have worked as an independent contractor; many times your payments to social security may have been under reported. If you find a problem, contact your local Social Security office right away, show them proof of your actual wages, and the record will be corrected. If your earnings have been very low, this may make the difference between receiving benefits and not receiving benefits. If you do have income that was not reported and you report it now you will have to pay taxes on that income. This can be particularly important for people who have tested positive for HIV but have not developed symptoms, so that any potential benefits will not be delayed by wage correction efforts.

Disabled widows, widowers, and children eligible for benefits as a dependent on a spouse's or parent's Social Security record receive an amount that is a percentage of the worker's Social Security benefit.

## SUPPLEMENTAL SECURITY INCOME

### The Nonmedical Rules of Eligibility

SSI is a program that pays monthly benefits to people with low incomes and limited assets who are 65 or older, blind, or disabled.

As its name implies, Supplemental Security Income supplements a person's income up to a certain level. The level varies from one state to another and can go up every year based on cost-of-living increases.

Social Security doesn't count all the income you have when they figure out if you qualify for SSI. Some exclusions include:

- $20 per month of most income
- $65 per month of wages and one half of wages over $65
- Food Stamps
- Home energy/housing assistance
- Financial Aid for school

If you work, there are special rules the SSA uses for counting your wages. Besides rules about income, people on SSI must have limited assets. Generally, individuals with assets under $2000, or couples with assets under $3000, can qualify for SSI. However, when Social Security figures your assets, they don't count such items as the home you live in, your car (unless it's an expensive one), most of your personal belongings, burial plots and burial funds up to $1500, and life insurance of $1500 or less. In Georgia you must earn less than $422 per month to qualify for SSI.

Your Social Security office can tell you more about the income and asset limits. For more general information, call the SSA at 1-800-772-1213 and request a copy of the booklet, SSI (Publication No. 05-11000) .

# HOW DOES SOCIAL SECURITY DEFINE DISABILITY?

What follows is an explanation of the criteria you must meet to be considered "disabled." First are the general rules by which Social Security defines and determines disability. Then there is information about how it applies to people with HIV infection.

## THE GENERAL DEFINITION OF DISABILITY

Disability under Social Security is based on your inability to work because of a medical condition. You will be considered disabled if you are unable to do any kind of "substantial" work for which you are suited. (Usually, monthly earnings of $500 or more are considered substantial.) Your inability to work must be expected to last at least a year or the condition that keeps you from working must be so severe that you are not expected to live.

For children, Social Security decides how the condition affects their ability to function, to do the things and behave in the ways that other children of the same age normally would.

**How Does This Definition of Disability Apply To People With HIV Infection ?**

A person with symptomatic HIV infection is often severely limited in his or her ability to work. In other words, if the evidence shows that you have symptomatic HIV infection that severely limits your ability to work, and if you meet the other eligibility factors, the chances are very good that you can receive Social Security or SSI benefits.

On the other hand, some people with HIV infection may be less impaired and able to work, so they may not be eligible for disability.

**CDC's Case Definition vs. Social Security's Listing for HIV Infection.**

The Centers for Disease Control and Prevention (CDC) and Social Security view HIV disease, including AIDS, from different perspectives, and therefore, there is no direct relationship between them. The CDC defines what it terms "severe HIV disease (AIDS)" for disease reporting and surveillance, epidemiological studies, prevention and control activities, and public health policy and planning. SSA must decide if HIV infection—even if it is not CDC-defined AIDS—results in a disability that restricts ability to work or to function in an age-appropriate manner (for a child).

The CDC recently revised its surveillance case definition of AIDS to include an absolute CD4 T cell count of less than 200 cells or a percent CD4 T-cells of total lymphocytes less than 14 percent. They also added pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer.

The final medical listing for HIV does not include a specific CD4 lymphocyte count as a criterion because there is no consistent correlation between a given CD4 count and how or whether an individual is functionally impaired by HIV. SSA has included guidelines for evaluating the severity of the other new conditions in the revised CDC definition (invasive cervical cancer, pulmonary tuberculosis, and recurrent pneumonia).

## HOW DOES SOCIAL SECURITY EVALUATE YOUR DISABILITY?

Social Security works with an agency in each state, usually called a Disability Determination Service (DDS), to evaluate disability claims. At the DDS, a disability evaluation specialist or disability adjudicator and a doctor follow a step-by-step process that applies to all disability claims.

First, the DDS specialists decide whether your impairment is "severe." This simply means the evidence must show that your disability interferes with your ability to work.

The next step in the process is deciding whether the disability is included in a list of impairments. This list describes, for each of the major body systems, impairments considered severe enough to prevent an adult from doing any substantial work, or in children under the age of 18, impairments that are severe enough to prevent a child from functioning in a manner similar to other children of the same age.

Because HIV research is a dynamic process and medical knowledge concerning the disease and its symptoms are constantly growing, Social Security continually updates its evaluation criteria for HIV infection. Recently, for example, SSA issued special guidelines for the immune system, including criteria for evaluating the claims of women and children with HIV infection.

If you have symptoms of HIV infection that are not specifically included in (or equal in severity to) the current guidelines, then DDS disability specialists will evaluate all available medical evidence to determine your ability to work. They will be looking for documentation of signs, symptoms, and laboratory findings that can result from HIV infection. They will also look for evidence of restrictions in daily activities caused by HIV infection.

## DOCUMENTATION OF HIV AND MANIFESTATIONS OF HIV

Social Security requires that the medical evidence must include documentation of the existence of HIV infection and documentation of its manifestations. A person may be determined disabled by HIV from definitive laboratory evidence or, presumptively, based on the clinical record. In both cases, if definitive laboratory evidence is not used, the documentation must be consistent with the prevailing state of medical knowledge and clinical practice and not conflict with the other evidence.

## PRESUMPTIVE DIAGNOSIS OF HIV AND MANIFESTATIONS OF HIV

When tests are not available, the documentation of HIV infection will rely on clinical history, physical examination, exclusion of other causes for the clinical abnormalities, and treating source opinion. When a manifestation of HIV cannot be diagnosed by laboratory evidence, a diagnosis may be based on clinical impressions and response to treatment. The pamphlet *Providing Medical Evidence for Individuals with HIV Infection* (SSA Publication number 64-037) may be helpful by describing how your Care Provider should document information in your medical record. You can obtain a copy of this pamphlet by calling 1-800-772-1213.

# HIV LISTINGS FOR ADULTS

In response to the many comments the Social Security Administration received about the proposed rules for evaluating HIV infection, they extensively revised the final rules from the preliminary listing. SSA reorganized and rewrote the listings to simplify them. The listing many times must use complex medical terminology to describe very specific conditions. This is done to make sure all applicants are evaluated equally by the same criteria. A summary of the listings follows.

## SIGNS

- Evidence of opportunistic infections such as Pneumocystis carinii pneumonia (PCP), Cytomegalovirus disease (CMV), or Toxoplasmosis of an organ other than the liver, spleen, or lymph nodes.

- Malignancies specifically associated with HIV infection such as Kaposi's Sarcoma with: extensive oral lesions; or involvement of the gastrointestinal tract, lungs, or other visceral organs, or any non-Hodgkin's lymphomas and Hodgkin's disease, or Squamous cell carcinoma of the anus.

- Recurrent bacterial infections like Mycobacterial infection caused by M. avium complex, M.Kansasii, or M. tuberculosis at a site other than the lungs, skin, or cervical or hilar lymph nodes.

- Pulmonary tuberculosis resistant to treatment.

- Severe or treatment-resistant syphilis or neurosyphilis.

- Multiple or recurrent bacterial infection(s), including pelvic inflammatory disease, requiring hospitalization or intravenous antibiotic treatment three or more times in one year.

- Documented weight loss (10% or more of baseline weight) or HIV Wasting Syndrome.

- Documented fevers greater than 38 C (100.4 F ) for one month or more.

- Candidiasis of esophagus, bronchi, trachea, or lungs.

- Conditions of the skin or mucous membranes with extensive ulcerating lesions not responding to treatment (e.g., dermatological conditions such as eczema or psoriasis, vulvovaginal or other mucosal candidiasis, condyloma caused by human papilloma virus, genital ulcerative disease)

- Histoplasmosis, at a site other than the lungs or lymph nodes.

- Salmonella bacteremia, recurrent non-typhoid.

- Coccidioidomycosis, disseminated or extrapulmonary.

- Cryptococcosis, extrapulmonary (Cryptococcal Meningitis).

- Strongyloidiasis, extraintestinal.

- HIV encephalopathy (Dementia) characterized by thought or motor dysfunction.

- Neurological manifestations of HIV infection (e.g., peripheral neuropathy) documented by:
  - -Paresis or paralysis
  - -Tremor or involuntary movement
  - -Ataxia (difficulty walking)
  - -Sensory disturbance (loss or change in sensation)

- Hepatitis with at least one of the following documented
  - -Serum Bilirubin of 2.5 mg. or greater for five months
  - -Esophageal Varices (major hemorrhage in the throat)
  - -Persistent Ascites (accumulation of fluid in abdomen)
  - -Liver biopsy confirming chronic liver disease

- Cardiomyopathy, with documented CHF (congestive heart failure)

- Nephropathy, (problem with kidneys) documented by:
  - -Proteinuria of 10 gm. in 24 hours (protein in urine)
  - -Hemodialysis or Peritoneal Dialysis
  - -Persistent elevation of serum creatinine to 4 mg. for at least three months
  - -Persistent Hematocrit of 30 or less

- One or more of the following infections resistant to treatment or requiring hospitalization or intravenous treatment three or more times in one year:
  - -Sepsis
  - -Meningitis
  - -Pneumonia
  - -Septic arthritis
  - -Endocarditis
  - -Radiographically documented sinusitis.

- Recurrent pneumonia and drug-resistant pulmonary tuberculosis (in the presence of HIV infection) are now “CDC AIDS.”

## SYMPTOMS

- Low energy, easy to get fatigued, generalized weakness that interferes with daily activities

- Persistent fevers/night sweats

- Dyspnea on exertion (shortness of breath)

- Persistent cough

- Diarrhea, lasting for one month or longer, resistant to treatment, and requiring intravenous hydration, intravenous alimentation, or tube feeding.

- Depression/anxiety

- Forgetfulness, loss of concentration, and slowness of thought

- Other symptoms such as headache, anorexia, nausea, and vomiting (possible drug side effects are considered, because many individuals are taking antiviral agents, immune modulators, or other medications that have serious side effects).

## LABORATORY FINDINGS

- Positive HIV antibody test (including confirmatory test ELISA and Western Blot)

- Leukopenia, lymphopenia.

- Other indicators of immune status such as elevated beta-2 microglobulins, detectable p24 antigen, etc.

- Inverted helper/suppressor ratio

- X-ray or imaging changes

- Microbiology and pathology reports

- Anemia documented by:
    - -Hematocrit persistently less than 30%
    - -Requiring transfusion

- Granulocytopenia documented by:
    - -Absolute neutrophil below 1000 cells/cubic millimeter and
    - -recurrent bacterial infection at least three times in five months

- Thrombocytopenia documented by:
    - -Platelet counts repeatedly below 40,000/cubic millimeters with
    - -At least one spontaneous hemorrhage requiring transfusion or
    - -Intercranial bleeding (in the head)

Another method that may be used to decide if your signs and symptoms qualify you for disability is the "repeated manifestation rule." "Repeated manifestations" are those that occur an average of three times a year, each lasting two weeks or more; or those that do not last for two weeks but occur substantially more frequently than three times in a year; or those that occur less often than an average of three times a year but last substantially longer than two weeks. Social Security may use this rule to measure impairment by functional criteria.

Finally, if a disability decision cannot be made on medical factors alone, the DDS specialists evaluate a variety of physical and/or mental limitations you may have that prevent you from working. These include:

- Your ability (or inability) to do **physical** tasks such as walking, standing, lifting, carrying, pushing, pulling, reaching, and handling objects; or

- Your ability (or inability) to perform **mental** tasks such as understanding, carrying out, and remembering instructions, responding appropriately to supervision and coworkers, and dealing with work pressures.

You will probably be asked to fill out a Daily Activities Questionnaire.

# EVALUATION OF HIV INFECTION IN WOMEN

Statistics show that there is an increasing percentage of women with HIV diseases. Social Security's new guidelines for the immune system recognize that HIV infection can show up differently in women than in men. In addition to the criteria outlined above, DDS disability evaluators consider gynecological problems when assessing the degree to which the disease affects a woman's ability to function. Examples of gynecological problems evaluators consider include:

- **Vulvovaginal Candidiasis (yeast infection)**

  Although this condition usually heals quickly with appropriate treatment, in women with weak immune systems the disorder may become chronic and poorly responsive to therapy.

- **Genital Herpes**

  Although the lesions usually occur in limited areas (such as the vulva), as HIV infection progresses, the herpes may involve more widespread anatomical areas and be resistant to typical therapy. If the lesions last longer than one month they may be considered disabling.

- **Pelvic Inflammatory Disease**

  Women can get infections in the pelvic cavity. The infection may spread more rapidly if an intrauterine device (IUD) is used to prevent pregnancy. In some women, particularly those infected with HIV, there may be resistance to therapy and recurrent episodes of inflammation and pain.

- **Cervical Cancer**

  This condition may take a more aggressive course in women with HIV infection and is considered disabling after stage two.

- **Condyloma caused by HPV**

  When condyloma caused by the human papilloma virus has extensive ulcerating lesions or if it does not respond to treatment they may be considered disabling.

# EVALUATION OF HIV INFECTION IN CHILDREN

Social Security has recently added special childhood disability guidelines for HIV infection. These guidelines recognize the fact that younger children with HIV infection can differ from adults, or even older children (age 13 or older), in the method of infection and in the course of the disease.

As with adults, some children may not appear to have the conditions specified in the guidelines, but they may have other signs and symptoms indicative of HIV infection which affect their abilities to grow, develop, or engage in activities similar to children of the same age. The listings for children include many of the same manifestations as in the adult listings. The listings provide child-specific documentation rules and manifestations specific to children.

Antibody testing for HIV infection is not definitive in young children. Therefore, SSA included alternative criteria that would help identify when infants who test positive for HIV antibodies are infected.

The pediatric listings parallel the adult listings when appropriate, but contain different criteria where manifestations of HIV in children differ from those in adults (e.g., neurological listing allows for resultant loss of previously acquired milestones, impaired brain growth, or progressive motor dysfunction). Most of the disorders listed for adults are the same for children.

The pediatric listing provides criteria for evaluation of growth disturbance in children with HIV infection and criteria for pathogenic bacterial infection(s).

The listing also provides criteria for lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia causing respiratory problems.

For children with HIV infection any other manifestations that meet the “repeated manifestation rule” may qualify them for disability. “Repeated manifestations” are those that occur an average of three times a year, each lasting two weeks or more; or those that do not last for two weeks but occur substantially more frequently than three times in a year; or those that occur less often than an average of three times a year but last substantially longer than two weeks.

For more information about disability benefits for children, obtain a copy of the booklet, *Social Security And SSI Benefits For Children With Disabilities* (Publication No. 05-10026) by calling 1-800-772-1213.

# DISABILITY: HOW YOUR CLAIM IS PROCESSED

## How Do You File For Disability Benefits?

You apply for Social Security and SSI Disability benefits by calling 1-800-772-1213 or visiting any Social Security office (all Social Security files are kept strictly confidential.). Identify yourself as a person with HIV/AIDS and notify them you wish to apply for disability. It would help if you have certain documents with you when you apply. But don't delay filing because you don't have all the information you need. SSA helps you get the rest of it after you sign up. The information you'll need may include:

- your Social Security number and birth certificate;
- Social Security numbers and birth certificates for family members signing up on your record;
- a copy of your most recent W-2 form (or your tax return if you're self-employed);
- If you're signing up for SSI, you will need to provide records that show that your income and assets are below the SSI limits. This might include such things as bank statements, rent receipts, car registration, etc.

You'll need to give SSA information about how your condition affects your daily activities. They will also need the names and addresses of your doctors and clinics where you've received treatment. Finally, a summary of the kind of work you've done in the last 15 years will be needed. If you have medical evidence such as reports of blood tests, laboratory work, or a physical, it would be helpful if you brought them with you. Included below are some guidelines for providing SSA with medical and vocational information that will help speed up your claim.

## What to Expect in Terms of Processing Your Claim

An HIV infection claim should be given prompt attention and priority handling. When you contact Social Security to apply for disability, you should receive an "appointment" to begin the application process within two days. Your "appointment" may be in person at your local office or you can apply over the phone. For many people applying for SSI with a medical diagnosis of symptomatic HIV infection, the law allows SSA to **presume** they are disabled. This allows Social Security to pay up to six months of benefits pending a final decision on the claim. You will qualify for this immediate payment if:

- a licensed physician confirms that the HIV infection is severe enough to meet SSA's criteria;
- you meet the other SSI nonmedical eligibility requirements; and
- you are not doing "substantial" work.

There is a special form *The Medical Report on Adults with Allegation of HIV Infection* (SSA-4814-14-F5) which can be completed by your doctor for presumptive disability. If you have symptomatic HIV infection and the SSA field office cannot provide immediate payment, a disability evaluation specialist at the DDS may still make a "presumptive" disability decision at any point in the process where the evidence suggests a high likelihood that your claim will be approved. (If Social Security later decides you are not disabled, you will not have to pay back the money you received.)

## What You Can Do To Speed Up The Processing Of Your Claim

You can play an active and important role in ensuring that your claim is processed accurately and quickly. The best advice is to keep thorough records that document the symptoms of your illness and how it affects your daily activities, and then to provide any of this information to Social Security when you file your claim. Here are some guidelines you can follow:

**Document the symptoms of your illness early and often**

Use a calendar to jot down brief notes about how you feel on each day. Record any of your usual activities you could not do on any given day. Be specific. And don't forget to include any psychological or mental problems.

**Help your doctor help you**

Not all doctors may be aware of all the kinds of information needed to document your disability. Ask your doctor or other health care professional to track the course of your symptoms in detail over time and to keep a thorough record of any evidence of fatigue, depression, forgetfulness, dizziness, and other hard-to-document symptoms.

**Keep records of how your illness affected you on the job**

If you were working, but lost your job because of your illness, make notes that describe what it is about your condition that forced you to stop working.

**Supply copies of all these records when you file**

Besides these records, be sure to list the names, addresses, and phone numbers of all the doctors, clinics, and hospitals you have been to since your illness began. Include your patient or treatment identification number if you know it. Also include the names, addresses, and phone numbers of any other people who have information about your illness.

## What Happens If You Return To Work

If you return to work, Social Security has several special rules, called work incentives, which provide cash benefits and continued Medicare or Medicaid coverage while you work. They are particularly important to people with HIV disease who, because of the recurrent nature of HIV related illnesses, may be able to return to work following periods of disability.

The rules are different for Social Security and SSI beneficiaries. For people getting Social Security Disability benefits, they include a 9 month "trial work period" during which earnings, no matter how much, will not affect benefit payments; and a 3 year guarantee that, if benefits have stopped because a person remains employed after the trial work period, a Social Security check will be paid for any month earnings are below the "substantial" level (generally $500). In addition, Medicaid coverage extends through the 3 year period after the trial work period, even if your earnings are substantial.

SSI work incentives include continuation of Medicaid coverage even if earnings are too high for SSI payments to be made, help with setting up a "plan to achieve self support" (PASS), and special consideration for pay received in a sheltered workshop so that SSI benefits may continue though the earnings might normally prevent payments.

These and other work incentives are explained in detail in the publication, *Working While Disabled . . . How Social Security Can Help* (Publication No. 05-10095). Call 1-800-772-1213 to obtain a free copy.

# HOW SOCIAL SECURITY BENEFITS RELATE TO MEDICAID AND MEDICARE

Medicaid and Medicare are two major government-run health insurance programs. Generally, people on SSI and other people with low incomes qualify for Medicaid.

## MEDICAID COVERAGE

In most States, Social Security's decision that you are eligible for SSI also makes you eligible for Medicaid coverage. (Check with your local Social Security or Medicaid office to verify the requirements in your state.)

State Medicaid programs are required to cover certain services, including inpatient and outpatient hospital care and physician services. States have the option to include other services, such as intermediate care, hospice care, private duty nursing, and prescribed drugs.

For more information about Medicaid, contact your local Medicaid agency.

## MEDICARE COVERAGE

If you get Social Security disability, you will qualify for Medicare coverage 24 months after the month you became entitled to those benefits. Medicare helps pay for:

- inpatient and outpatient hospital care;
- doctor's services;
- diagnostic tests;
- skilled nursing care;
- home health visits;
- hospice care; and
- other medical services.

For more information, please see the "Government Assistance" section in this workbook or obtain the booklet *Medicare* (Publication No. 05-10043) from 1-800-772-1213.

# PUBLICATIONS AND RESOURCES FOR DISABILITY, MEDICAID AND MEDICARE

## PUBLICATIONS

*Disability* (Publication No. 05-10029)

*Guide to Social Security and SSI Disability Benefits for People with HIV Infection* (Publication No. 05-10020)

*Medicare* (Publication No. 05-10043)

*Providing Medical Evidence for Individuals with HIV Infection* (Publication No. 64-037)

*Social Security and SSI Benefits for Children with Disabilities* (Publication No. 05-10026)

*SSI* (Publication No. 05-11000)

*Working While Disabled...How Social Security Can Help* (Publication No. 05-10095)

## PHONE NUMBERS

Social Security Administration 1-800-772-1213

- to order pamphlets or ask questions concerning Disability and Medicare
- to locate local offices

Georgia State Department of Medical Assistance:
In Atlanta 404-656-2515
In Georgia 1-800-282-4536

- for information on Medicaid

# FOOTNOTES

1. by Victor Steve Moore, 1993
2. This section updated and revised by Christopher D. L. Miller, 1994

Revised by Jeff Graham, May 1995

# NOTES

Active vs. Passive
Proactive vs. Reactive
Assertive vs. Aggressive

# EMOTIONAL AND PSYCHOLOGICAL ISSUES

# I AM ME[1]

I am Me

In all the world there is no one else exactly like me

There are persons who have some part of me but no one adds up exactly like anyone else

I own everything about me
My body, including all its thoughts and ideas
My eyes, including the images of all my eye beholds
My feelings, whatever they may be– anger, joy, frustration, love, disappointment, excitement
My mouth and all that comes out of it – words – polite, sweet or rough, correct and incorrect
My voice, loud or soft
and all my actions whether they be to others or to myself

I own all my triumphs and successes all my failures and mistakes
I own my fantasies, my dreams, my hopes, my fears
Because I own all of me
I can become intimately acquainted with me
I can love me and be friendly to me and all my parts

I know there are aspects about myself I do not know and there are parts of me that puzzle me

As long as I am friendly and loving to myself , I can courageously look for the solutions to my puzzles, and continually look for ways to find out more about me, how I look and sound, what I say and do, and how I think and feel

No one else looks and sounds, says and does, and thinks and feels exactly like me

In being well acquainted with myself
Loving myself and being friendly with myself
I can then make it possible for all of me to work in my best interest

However I look and sound, whatever I say and do, and whatever I think and feel at a given moment is me, it is authentic and represents where I am at that moment in time.

# LIVING IN SPITE OF HIV 2

*Operation Survive was created by a special man with his own unique perspective on living with HIV disease. He has been an inspiration to many and the driving force in the initial development of this self empowerment program. We all adapt to situations in our own special way and we wanted to share with you how Roy helped us bring this message to you. Roy wrote the following article when he created the first Operation: Survive! workbook.*

Learning to live with HIV disease is a process, it is not something we do once and it's done. It is a continuous learning process that we must face every day, which we must experience and grow through. Instead of the term living with AIDS, I prefer the term living in spite of AIDS.

Learning to live with HIV disease is not easy. For most of us it will be the most difficult and challenging thing we have ever been faced with. HIV disease changes or affects every aspect of one's life, and change whether good or bad creates a significant amount of stress. Living with or manage a chronic illness is not easy or fun. However, it can be done. It will require a great deal of effort and determination. One might say, ”but, it isn't fair. I'm sick, why should I have to expend so much energy and effort?“

The reality is that it isn't fair, it stinks. But we have to deal with it and others can't do it for us. The good news is that there is life after being diagnosis HIV+.

The initial diagnosis is a very crucial point in one's life. Receiving a diagnosis of HIV disease, for most of us, is an earth shaking slap in the face that often brings us to our knees. I often compare being diagnosed with HIV to running head first into a brick wall. We hit the wall, then fall flat on our behinds. We sit there for a while shaking our heads trying to figure out what hit us so hard. Slowly we get up on one knee, then slowly the other knee. Feeling more stable, we then stand on one foot and finally the other foot. Realizing that we are still physically in one piece, we begin to walk around. Because of the psychological trauma, we usually walk in circles for varying amounts of time. Eventually we work though the emotional traumas or someone takes us by the hand and leads us though the confusion.

It is very important for us to realize that this is part of the process and allow ourselves time to recover. Some of us may take a short time, others a long time, and some will never get beyond this point. We must realize that it is okay for us to be confused, angry, fearful, or depressed during this initial period after diagnosis. We must allow ourselves time to process what has happened before we can move on. You can expect to be overwhelmed with a variety of emotions, but we must not stay overwhelmed forever. The old adage, ”big boys don't cry“ is a crock! We do and will cry and guess what? It is good for us. Crying can be very emotionally cleansing. Crying releases stress and tension. So go ahead and cry when and if you need to. If you are still crying six months later, you may have a problem you want to address. It's okay to be down, it's not okay to stay down.

A turning point for many of us is when we reach the point where we are ready to move past being overwhelmed and into action. Where do we start? There are so many issues, so many problems, and a multitude of choices to be made. DON'T try to solve all your problems and address all of your issues at once. Take them one at a time and one day at a time. There are many choices and difficult decisions to be made that will lead us on this sometimes confusing path.

Those individuals who are truly living well in spite of HIV disease, have made or are making some very deliberate choices, decisions, and commitments to themselves. We will make the decisions and choices not a tiny virus. However, we often allow this virus much more control or power than it really has. WE allow other people to make our decisions for us. This can leave us feeling out of control, usually because we don't have enough information to make a wise choice or decision.

If we are going to be an active participant and not a "patient" then we have to accept the fact that we have HIV disease. Oh no, not acceptance! This is a biggie for most of us and this is where some of us stumble. Acceptance does not mean giving up! Acceptance goes something like this, "Yes, I have HIV. Yes, it could be fatal, but I have today and I'm going to get the most out of life this day." Giving up on the other hand goes like this, " I have HIV. What's the use in trying? I'm going to die anyway so I'll just sit back and wait to die." A tough decision, but it's all ours. Which will it be?

We must also learn to accept the things we cannot change or control. We must realize that there will be situations or problems where there simply are no answers. Save your energy for those things you can change, accept those things you cannot change, and hopefully have the wisdom to know the difference. We have to accept the things we can't change and learn to let those things go. We cannot afford to waste our time and energies hanging on to excess baggage. We don't need dead weight to carry around.

One reason acceptance is so difficult is because once we accept our situation, then we must take responsibility for it. We are responsible for gathering information so we can make wise decisions and choices. This is no small task. We are responsible for getting medical attention when we need it. We are responsible for getting emotional or psychological counseling and support when we need it. We are responsible for changing our life-styles, for taking better care of ourselves. We are responsible for reaching toward a positive direction in our lives.

A big part of taking responsibility will be to develop a game plan or strategy for how we are going to fight HIV. This will involve much effort, gathering of information, education and long and short range planning. To make informed decisions we need as much information as possible. We must educate ourselves about HIV disease and its progression, how this virus works, how it attacks us, and how it can and cannot affect us.

You must also know who our allies are. Who will be there to support us in this battle? Who will fight on our side? We must talk with our friends and family. We need to come out to those people we think may be supportive. I know this is a risk. However, I believe it is better to find out who is going to stick by us from the beginning, not when we are in the middle of dealing with HIV. In the event we do lose some support from friends and family, we have time and opportunity to build a new support system around us. We will need all the support we can muster to fight this disease.

Having learned who and what our enemy is, who our allies and supporters are, and established our support system, now it is time for action. We must set up our line of defense. This will require more information gathering. How are we going to defend ourselves against HIV? What life-style changes need to be made? What preventive treatments or therapies are available, which ones do we want to take? We need to beef up our forces, start taking good care of ourselves, eat well, rest, stop abusing our bodies with alcohol and drugs and get some exercise within our limitations. We need to find out what we can do to make our bodies and minds stronger. We may have to regroup and change our plans, but we cannot afford to become discouraged or give up. We must keep fighting.

One of the most effective weapons we have is attitude. Give HIV a good dishing of attitude. Learn to take anger, frustration, and fear, and direct it toward fighting HIV. Doing this will give us the energy we need to fight and will help us not to direct our anger toward those people who are trying to help us and fighting with us. Some of my friends would tell you I'm just too stubborn to give up. This virus may make me sick, but I'll be damned if I will let it make me miserable. We need to keep our sense of humor. I plan to fight as hard as I can, to live as long as I can if for no other reason than to be a pain in the butt to those bigots who wish me dead, or to make those people who have abandoned me as uncomfortable as possible. Vicious? Maybe. I call it survival.

We must help our brothers and sisters prepare for their fight with HIV. We must support them. We must help them to their feet after diagnosis. We must teach them what we have learned in our fight. We must encourage them to fight. We need to be part of the solution, not just part of the problem. There are many ways to help. We can volunteer with numerous agencies and organizations. Get active and get involved. After all this is our battle. If we are not willing to fight then how can we expect others to fight for us?

There are some things that hinder or hold us back in our struggle to live in spite of HIV disease. One thing that will definitely keep us in a holding pattern is denial. I sometimes call this the Ostrich Syndrome. When we are uncomfortable with dealing with a situation, we simply ignore it or put off dealing with the issue. We can do this but the problem or issue probably will not go away and will keep coming back to haunt us until we do confront it. Another danger of denial is that it may keep us from getting the education or information we need to survive. This lack of information can and will kill us. For example, it is imperative that we know what the symptoms of the opportunistic infections are (such as Pneumocystis Carinii Pneumonia) so we can get prompt medical attention. If we don't know what the danger signals are we may overlook important symptoms that could cost us our lives. In this instance, what we don't know can kill us!

Another problem that can keep us from living in spite of HIV disease is isolation. Many of us isolate ourselves from our friends and those who would be supportive because we fear losing them or we are not comfortable with our own situation. Don't do this! We need the support of our loved ones. We need to be with those people who want to help. We need to be with other people who are in the same boat. There are many safe places that we can take advantage of where we can socialize with others with HIV disease, meet new friends, and ease the feeling of being alone in this war.

Then there are those of us who buy into the garbage that society throws at us. We believe that we somehow deserve this disease. We think of ourselves as lepers. You may feel guilty or ashamed of our medical condition. We should not do this to ourselves. I have AIDS because I have a virus that is damaging my immune system, not because I'm gay! We should not allow anyone to treat us like second class citizens because of our disease or our life style. If I am a leper, then I will hold my head up proudly and be the best damned leper I can be.

Statements made in this article are my personal opinions, perspectives and philosophies. I could be off-base. I could be wrong. God knows I've made my share of bad decisions and mistakes.

# POSITIVE ADAPTATION 3

In the early 1970's Callista Roy developed a model for nursing practice. This model was based on the simple principle that the primary goal of nursing should be to promote positive adaptation to a constantly changing environment. Each person in the world must adapt to their own set of circumstance and deal with life on life's terms. Sometimes the response to a changing world is illness or maladaptation. According to Roy it is the responsibility of nursing to help people adapt their lives to deal with and overcome illness. We all bring special tools based on our experience to this task. Each person is partly made up of their past experience that will influence how they will adapt to the event in their life.

I trained as a nurse using this model and for many years now it has served me well in helping me adapt to life with HIV. In this section I will introduce you to some of the concepts of the adaptation model that I hope you will be able to use in your life. One of the outstanding features of long term survivors of HIV disease is the ability to adapt to their changing world and move forward as an active participant in life. This process is different and special for each individual but there are some common traits of people living well in spite of HIV.

When long-term AIDS survivors compare their experiences, they find that they have many characteristics in common. According to a study conducted by Dr. George F. Solomon, a researcher in the field of psychoneuro-immunology at the University of California, they share the following beliefs and characteristics:

- They are realistic and accept the AIDS diagnosis but do not take it as a death sentence.
- They have a fighting spirit and refuse to be "helpless or hopeless."
- They have made positive changes in their life-styles.
- They are assertive and can get out of stressful, unproductive situations.
- They are aware of their psychological and physical needs, and they take care of them.
- They can talk openly about their illness.
- They have a sense of personal responsibility for their health; they see themselves as partners with their physician, NOT just a passive receiver of treatment
- They are altruistically (unselfishly) involved with other people with living AIDS.

## Basic assumptions of the Roy adaptation Model

An assumption is a statement accepted as true without proof. Now I know you are all probably thinking "what happens when we assume? We make an ASS of U and Me" well this is not one of those assumptions. All theoretical models have basic assumptions. The assumptions behind the Roy adaptation model are based on the model's approach to the concept of the person and the process of adaptation to life.

**Assumption One: The person is a biopsychosocial being**

This means that we are all made up of three primary components

- Biological Component, our anatomy and physiology the workings of our body and how it responds to change.
- Psychological Component, our self concept, the values we view the world with.
- Social Component, our patterns of interactions with others, the tools we use to communicate our needs.

Whatever situations we may encounter a person will need to adapt in all three of these areas. It is very rare that any stimuli in life will only affect one component of the biopsychosocial being.

**Assumption Two: The person is in constant interaction with a changing environment.**

The world around us is in constant change. The weather is different from day to day and season to season. Our daily activities change, the people and situations we encounter on a daily basis change. Finding out you are HIV + has probably created profound change in your life.

**Assumption Three: To cope with the changing world the person uses both innate and acquired mechanisms.**

- Innate mechanisms are those you are born with. For example when you are cold your body shifts blood to the internal organs to keep them warm. When you are working out or get hot your body circulates blood close to the skin and perspiration forms to conduct unneeded heat away from your body.
- Acquired mechanisms are those that you learn. For example some people learn when they become angry it helps them to exercise to calm down, or that taking an afternoon nap helps them to interact well with others in the evening.

You may have many wonderful tools that you have learned to help you adapt to live with HIV. Unfortunately many of us were out of the room when the instruction manual for life was handed out. For us an important part of this journey is to learn new tools to adapt to life.

**Assumption Four: To respond positively to change the person must adapt.**

Change is always difficult. Even positive changes cause stress. During the period of fear and uncertainty that can accompany change, it can be helpful to remember that positive changes will never lead us astray. The uneasiness will pass once you've had the chance to get used to the change.

# SELF EMPOWERMENT

One of the most basic adaptations that many people living with HIV must make to survive is called self empowerment.

**Self-empowerment is the act of taking control of our lives.**

This can be evidenced by behaviors such as:

- Self-education through identifying and utilizing available resources and information.
- Gaining self-knowledge/acceptance/understanding to enable us to make life enhancing choices.
- Assuming personal responsibility for our own well-being.
- Advocating for the rights of ourselves and others affected by HIV.
- Accepting our HIV status without taking it as a death sentence.
- Striving to be a positive example, role model, and/or community leader for others living with HIV.
- Creating active partnerships with healthcare and service providers.
- Respecting others' opinions and choices.

Each of us needs to develop a personal definition of self-empowerment and implement it in our own life.

# YOU ARE NOT ALONE [4]

Maybe you tested HIV positive very recently, or maybe you've known for some time, but this is the first time you have reached out for information or support. You need to know that YOU ARE NOT ALONE. There are an estimated 1.5 million people who are HIV positive in the United States. You will need to learn what information is available, and work to make informed choices about your health and you life.

HIV positive people now live fulfilling and happy lives. Many are healthy and show no symptoms of disease. Some have chosen to take certain treatments and drugs that show promise to preserve and lengthen their lives. So as serious as this is, THERE IS HOPE! You do not have to look at testing HIV positive as though you've just been given a death sentence.

IT'S A GOOD THING YOU FINALLY FOUND THIS OUT! As upsetting as testing positive may have been for you, you're better off knowing, so you can learn about this virus and decide how you are going to adapt to this change in your life. As a biopsychosocial being remember to care for all of you and not just one part. The fact that you were tested for HIV shows that you care about yourself and reading this workbook shows that you are concerned about your health. Give yourself some credit. You have taken important first steps to take care of yourself and you should be glad.

Years ago, those who tested HIV positive had few places to turn for support. These people felt like they were hanging in limbo. The only information anyone could give them is "we just don't know." Fortunately, much has changed. We know more about HIV now and many organizations have formed around the world to offer support and information to people living with this virus. Many have already faced the questions inherent in living with HIV, and many will follow. You don't have to face this by yourself. Your path will be individual and based on your own life experiences but you walk with many others. There are many hands reaching out to help you. Remember, you are not alone!

## Your Emotional Health

Finding out that you are infected with HIV is usually overwhelming. Even if you had suspected for some time that you were infected, actually discovering that you are can be a very traumatic experience. Testing positive for HIV has led some people to choose to quit their jobs, quickly write out their wills, and say good-bye to their friends and family. Many people then find out that they are not sick and will probably live for years to come. It is common to perceive these test results as an immediate death sentence. This is simply not true and you can adjust and adapt your thinking about HIV.

What you are feeling now is perfectly normal. Anger, fear, guilt, confusion, numbness, depression are completely natural reactions to the kind of news you've heard. If you've known for even several weeks, you may find yourself having a normal kind of day, then suddenly you remember that you're HIV positive. It is very common for this kind of realization to just "hit you in the face" out of nowhere over and over. You're not going crazy if this happens to you. It's happened to all of us. The first year after I was diagnosed, I would cry at Kodak commercials. Your moods may swing from profound sadness one moment to extreme anger the next. That's normal, too.

While there are many ways to deal with all these feelings, the first step in getting through this kind of emotional turmoil is to acknowledge what you are feeling. Some of the tools you may want to use are talking to a close friend or writing in a journal. One possible reaction is numbness -when you don't seem to be feeling anything. Don't be surprised if you find yourself going through the day in a state of shock. Even if you don't know it your mind has acquired ways to help you incorporate shocking new information. Allow yourself to feel nothing. It may take time to get in touch with all your feelings. One of your innate adaptation mechanisms may be to "turn off" to allow you time to adjust to a change in your environment.

If you're feeling angry, this is fine. You have every right to be angry and a lot to be angry about. This little virus is threatening your very existence and shaking up your whole life. It's okay to express this anger. If you're feeling fearful, acknowledge your fears. You're thinking about things that would make anyone fearful. YOU ARE ALLOWED TO FEEL THE WAY YOU ARE FEELING! Don't be hard on yourself or think that you have to be strong. "You don't have to be anything."

## FEAR OF SICKNESS & DYING

Almost everyone is afraid of getting sick or dying. You may have never really considered the possibility of your own death. Now suddenly you're faced with HIV and your mortality becomes very real. You may be very afraid of pain, of becoming unattractive to others. You may be afraid of hospitals. Your reaction to the idea of getting sick or dying could go several different ways. You may decide that you're definitely going to live and that there is no way this virus is ever going to "get you." This is a form of coping called denial, refusing to face some of the possibility of living with HIV. If you find yourself feeling this way, try to keep in mind that having hope to go on with your life is good. However, it can become dangerous if it keeps you from seeking essential medical care or prevents you from taking care of your biopsychosocial needs.

The other way you might choose to deal with the subjects of sickness and dying is by deciding that you are absolutely going to die and there is nothing you can do about it. If you go this way, you may find yourself fantasizing about your own sickness and death at the hands of HIV or AIDS. You need to keep in mind that there are many people who are HIV positive who are living productive and happy lives. You can choose to be one of them. It's good to face the possible consequences of this infection, but not to the point that living today becomes less important than what you fear may happen in the future.

## STARTING OVER

One of the truths of testing HIV positive is that once you know, you can never NOT know again. For bad or for good, your life will always be different in some ways now. You may be experiencing great feelings of loss about this. You may feel that certain areas of your life are now in the hands of doctors, labs, and insurance companies. This can make you feel as though you have less control over your own life and may cause you incredible anxiety. Remember the idea of self empowerment and bring those behaviors into play.

Know this: You do not have to give up control of your life. By arming yourself with information and deciding what is right for you, you will soon realize that you're still the same person you were. It is YOUR life, YOUR body, YOUR health, and no matter how well meaning your family, friends, or even your doctor may be, they are only a part of the answer to what you do next. Allow yourself to take time to decide what you want to do, then do it.

# HEALING AS A PROCESS 5

Healing is a process. There are documented cases of healing that have occurred miraculously and instantaneously. More often, however, it is a lengthier process. What we generally consider as healing is the elimination of physical symptoms. In reality, however, physical symptoms are only one part of the problem.

Hundreds of years ago scientists and theologians decided that the body, mind and spirit were totally separate entities whose symptoms were not related to each other. Because they saw each individual as being made up of three unrelated components, different groups took responsibility for each part. The body came to belong to the physician, the mind to the psychologist or psychiatrist, and the spirit to the clergy.

Because of these divisions, we have gone for decades not seeing any relationship between someone's psychological or spiritual well-being and their physical condition. In the early 70's stress studies began to show that as many as 90% of the visits to physicians' offices were actually for problems that were caused by stress. This resulted in greater research to try to understand how the mind and body work together. The more in-depth this research became, it resulted in a growing understanding that the spiritual well-being as well as the psychological status of a person contributed to their overall health and wellness.

Many textbooks, articles, and workshops are available at the present time that touch on many of the psychological and spiritual principles that are present in healing. These include: love, positive attitudes, hope, visualization, becoming empowered, prayer, being with others, and giving up anger and fear. Studies have shown that working to develop or enhance any of these psychological spiritual areas will likely improve your physical well being.

True healing, however, is a process. It is a process of transformation: transformation that results in healing - frequently of the whole person - body, mind and spirit.

The process of healing is much like developing a cocoon of protection around you. Several years ago a child was born without a functioning immune system. This system is the body's natural defense system against pathogens (germs) and is made up of types of white blood cells called lymphocytes (T-cells, B-cells, monocytes, macrophages, Natural Killer cells). The immune system protects the body from invading diseases. Doctors created a germfree environment in which the child could safely live. This bubble kept bacteria-free oxygen inside and things that could be deadly to his immune system outside.

The process of transformation is a similar process of building your own natural protective shield. The difference is that your shield goes with you out into the world and protects you, but does not interfere with your movement. Developing the shield involves developing your thoughts and behaviors in a way that creates the natural healing environment that protects against harmful invaders, keeping them firmly placed outside the shield without the ability to puncture your protective coating.

This transformation is also about discovering that inside the shield is joy, laughter, happiness, bliss..and healing.

# TAKING CONTROL OF YOUR MIND 6

The most powerful healing agent you have control of is your mind. The immune system is intimately tied to your attitudes, outlooks and thought processing. Research has shown that it is not the actual events or level of stress you may be experiencing that influences your body's processes. Instead it is your perception, impression, or reaction to them that influences how your body reacts.

The body responds to your thought patterns by producing chemicals that either stimulate or reduce activity in your nerves, muscles, and glands. Messenger molecules that are extremely sensitive to thoughts and reactions create a complex communication system that influences the total functioning of the brain and body. Some thoughts result in chemical reactions that enhance immune system operation; other thoughts result in chemical reactions that have a detrimental effect on the immune system.

An important part of your role in the healing process is to learn to take control of your thought processing so that your mind creates those things that help your immune system rather than harm it. Reactions and attitudes that have been found to be harmful to your immune system include: fear, holding onto anger, anxiety, depression, hopelessness, a feeling of loss of control, and a negative outlook on life. Factors that enhance immune system functioning include; love, hope, faith, a sense of gratitude, and not harboring anger, resentments and unforgiveness.

Developing the mind set for healthy immune functioning is part of the process of a healing transformation. Each part is more likely to become a stable part of how you think if you take it a step at a time. The most important first step you can take is to change the lenses through which you view the world.

Everyday we have a choice of how we see the world. We can look at the glass as half full or half empty. By developing a world view that sees things from a "what's working" perspective you can do great things for your attitude, outlook, and how you feel, as well as for your immune system.

It's very easy, especially when difficult circumstances present themselves, to start seeing everything that's wrong with life, your body, your circumstances, your friends, and other aspects of your life. Before long you get into playing the game Eric Berne, M.D., called "Ain't It Awful." You and your friends get into the habit of comparing horror stories of who has the most to complain about. From this position your immune system is jeopardized and your whole outlook creates a mode of depression and anxiety.

Instead of giving in to this dangerous game, choose instead to see everything that's working. In the beginning it may be difficult because of the negative habits that are in place. Push yourself to find the things that are positive. Make a list and keep pushing yourself until the positive list is longer than your negative list.

A second step in changing your mind to the mindset in which healing can best occur is to begin seeing the world though eyes of wonder and gratitude. The world is really a beautiful and amazing creation and there is much in your life that you have to be thankful for. Target as a goal awakening everyday with thoughts of the wonderful things you have to look forward to, and all the abundance you have received.

Norman Cousins conducted a study in which individuals intentionally changed their thoughts to a more positive world view. Within five minutes this resulted in an average increase of 53% in various positive immune system components. This ranged from a low of a 30% increase in precursor Natural Killer (NK) cells to a high of a 200% increase in antibody coded T-cells. In addition to seeing the world from a what's working position and with eyes of wonder and gratitude, begin visualizing positive outcomes regarding your disease. Don't allow negative thoughts to come into your mind. Gently send them away and substitute a positive thought.

Deal with smart present day realities like making a will - then plan for long-term outcomes, such as your 81st birthday party. Guided visualizations that help you see your body getting stronger, your immune system at peak capacity and your health as excellent do more than just make you feel good.

A study of individuals who were fighting a cold virus found that when they were asked to visualize lymphocytes fighting cold viruses, their T-cell levels increased.

A longitudinal study at the University of California at San Francisco found that AIDS patients with pneumocystis pneumonia who were long-term survivors had an excellent ability to view problems in optimistic ways and believe they have control over them. Individuals with a chronically negative attitude have been found to have lower levels of helper T-cells.

Another study looked at 280 men and women. They found that those with a negative attitude had significantly lower immune function in both T-lymphocytes and Natural Killer cells.

Consequently, developing a positive attitude is not just a pleasant thing to do. It can enhance your overall immune system and also provide the background against which your healing potential is greatest.

# SEVEN PHASES OF LIFE [7]

For many people when they find out they are HIV positive a journey begins to compress a whole lifetime of growth into a very short time. Erickson, a developmental psychologist, outlined seven phases of life with specific goals to achieve in each phase. Before realigning all of your priorities in life it may be helpful to assess where you are. Erickson's phases of life can help in a general way with this process. Knowing your own strengths and weaknesses can be a great asset to you in adapting to your changing life.

**TRUST VS. MISTRUST** (BIRTH TO ONE YEAR OLD)

This is when we develop basic trust that our needs will be met by our environment. The primary factor that influences the achievement of this goal is the kind of care our parents or significant other gives us.

**AUTONOMY VS. GUILT AND SHAME** (ONE TO THREE YEARS OLD)

Establishment of self separate from others. Major developmental tasks include learning to walk, talk, and feed themselves.

**INITIATIVE VS. SENSE OF GUILT** (THREE TO SIX YEARS OF AGE)

This is the rapid growing phase when a child learns the difference between male and female roles and the development of self concept; who you are in society.

**INDUSTRY VS. INFERIORITY** (SIX TO THIRTEEN YEARS)

This is the phase when children learn about competition and develop the tools needed to move out of the family into the world at large.

**IDENTITY VS. ROLE CONFUSION** (THIRTEEN TO NINETEEN)

Who am I in the world? What do I want to do with my life? This is when many people chose a career or pursue higher education.

**INTIMACY VS. ISOLATION** (TWENTY TO THIRTY–FIVE YEARS OLD)

Form lasting and significant relationships with a partner. Learn to give and receive love.

**GENERATIVITY VS. STAGNATION** (THIRTY FIVE TO SIXTY YEARS OLD)

Develop the role of teacher or guide to those who are younger.

**EGO INTEGRITY VS. DESPAIR**

Acceptance of life. Learning to accept help and release attachments. Primary characteristics are pride or regret.

Knowing where you are today and recognizing where you may need further growth can help guide you along the path of rapidly changing priorities. Before making major changes in your life, get the support and input you need to make informed choices. Take your time and think through each change carefully. Many HIV positive people have adapted their life in positive and self affirming ways. Some people change their habits around drinking, recreational drug use, or smoking. Some have gotten out of relationships that cannot support them or quit jobs that put them under too much stress. Facing the possibility of getting sick or dying has made many of our lives better because it has made us take action in areas where we have said in the past "oh I'll change that tomorrow" but tomorrow never seems to come.

There is an entire generation of men and women in our society today that are working with the tools and concepts of Generativety and Ego Integrity well before they have turned forty. Mortality can be a great mutilator! Having to deal with HIV has made many people wise beyond their years.

Some people blame themselves for being HIV positive. This kind of guilt and self-hate can be very destructive. No matter how you were infected, whether by sexual contact, drug use, blood transfusion, or some other way, you did not intentionally go somewhere to get yourself infected with HIV — so why beat yourself up? HIV is a disease, not a question of morality. You are facing many things right now and you don't need to be punishing yourself for testing HIV positive.

Grief, or extreme sadness, is one of the emotions that many HIV positive people face at some point. You may be grieving for yourself, facing the possibility of your own death. You may be grieving for others, this virus is not only affecting our lives, but the lives of those we love. Many of us have lost friends and loved ones to HIV, or have people in their lives who are also learning to live with HIV. If you sense this grief within you, you can allow yourself to feel it and even express it in some way. You might try writing down how you feel, or if you can, allowing yourself to cry. These feelings are valuable and normal. Ignoring these feelings will not make them go away. You must incorporate these feelings into your life.

You may also feel that you are now damaged in some way. You might think that no one will want to touch you or love you or that you are less than desirable because you are HIV positive. You may feel that you will never be able to love again, that no one would want to be with you if they knew that you were HIV positive.

You are still a valuable person, capable of giving and receiving love. You can make your own decisions, relax, and enjoy each day. This may be a struggle and you may have to find new ways of coping with daily life, learning to adapt to HIV is going to be a journey not a destination. Many of us have been raised with the idea of "rugged individualism," that we must face things on our own, that this is what "strength" is all about. Asking for help or reaching out for support is sometimes viewed as being weak. Consequently, a very common response to testing HIV positive is withdrawal. We isolate ourselves, hiding the news of our HIV status. This can be very painful. You have value and deserve help.

Your life does not have to be gloom and doom. It is possible to have a very positive attitude as a person living with HIV — thousands are doing it right now. It is much more difficult to get on with your life and live happily if you're trying to do it alone. There is no need for you to handle this all by yourself, and it's probably a mistake to even try. You are not the only person facing this. There are a number of organizations and individuals ready to assist you. Learn who they are, what they offer, and start making decisions about the kind of support you need or want.

Hearing how someone else has adjusted to testing HIV positive can help you realize that life is still good, and that you can still have love and laughter. You just might be surprised to learn how your own sharing can help others. We share so many issues together and each voice can be a source of support.

Support groups, like those at AIDS Survival Project, are a powerful means of learning to cope with this new beginning. There are support groups offered by HIV/AIDS organizations across the country. If you don't know of an HIV/AIDS organization in your area, call a peer counselor at AIDS Survival Project at (404) 874-7926 for a referral. If there is no support group in your area, you may be just the person to get one going! You could always talk to your physician or a local AIDS organization to get the ball rolling. Just remember that those thousands of people living successfully with this virus are individuals who have reached out to get the help they needed. Wherever you are, you can FIND support, or the means to help you create it. It just doesn't make sense for so many of us to face the same issues without sharing and supporting each other.

# WHO DO I TELL? 8

After being introduced to all this information about the importance of sharing and getting support I'm sure you are thinking about how to tell people about your HIV status. We have all had to face this decision. Each person must look at their own circumstance to decide how, when, and who to tell. First lets look at what the clinical practice guidelines from the US Department of Health and Human Services for the Evaluation and Management of HIV infection says.

HIV status is a very personal thing, and telling other people that you have HIV infection may be one of the hardest things you will ever have to do.

When someone first finds out they have the virus that causes AIDS, they may feel sad, depressed, ashamed, or afraid. Telling other people about their HIV infection may mean that they will get more support and help from others, but it can also lead to problems.

Local or state laws may require that a health care provider report HIV status to the health department. Otherwise, a person's HIV infection should be kept confidential, unless they decide to talk about it. In Georgia, there is a law that states that an HIV infected person MUST tell their sex partner about their HIV status prior to having sex.

Health care providers can help a person decide whom to tell and help them tell them once they have decided to do so. Peer Counselors at AIDS Survival Project can also help. Some people a person may want to tell include:

- Sex partners
- Persons with whom they inject drugs
- Family
- Friends

In today's society everyone should talk with their sex partners about using condoms for safe sex and about the risks of having a baby with HIV. If a person cannot stop using injected drugs, they will want to discuss the danger of sharing needles or works, and find out where to get clean needles or how to clean needles.

Many people want to talk with members of their family about how their health condition might affect them. Some people also choose to tell coworkers, neighbors or members of their church. If they are students, they may choose to tell people at school, such as the school nurse, administrators, teachers, and classmates.

Some people with HIV choose not to talk about their health, and that is all right, too. It's their choice.

# TO TELL OR NOT TO TELL
# MAKING THE DECISION TO DISCLOSE YOUR STATUS ,

A month after finding out he is HIV-positive, Test Positive A ware (TPA) member Rich Knibbs was lying in a hospital bed, under treatment for thrombocytopenia—low platelet count  His mother sat nervously on the edge of his bed, Indiana dust still on her shoes from the hurried trip north. Even though she was a registered nurse, Rich knew she had no clue that he was even gay, much less infected with HIV. With 100 mg. of Demerol goading him on, Rich groggily decided to break both pieces of news to her at the same time from his hospital bed.

"She took it very well-considering," Rich says. "She told me she'd tell all my brothers and sisters for me, but I wanted to do it myself."

No matter how they find out, informing your close friends and family of your HIV status can be at turns terrifying, exhausting, and liberating or all simultaneously. Although considerable research has shown that support from friends and family can buffer the negative emotional and physical impact of stress, questions surrounding disclosure in and of themselves can cause stress: Who do you disclose to? Should you disclose early or late in the disease process? How are people going to react? Do you have to disclose at all? Only you can answer these questions. Here are some pointers that may help.

## WHEN TO TELL

If you're not sure when to tell close friends and family your status, here are a few indicators that you're ready:

- You have come to terms emotionally with your HIV status.
- You can identify a specific reason for wanting to tell someone, such as a past, current, or potential sexual relationship.
- You're planning for the future, such as creating powers of attorney, and you want family and friends involved.
- You need emotional support.
- You're ready to share other issues in your life, such as sexual orientation or drug use.
- You need financial support.
- You feel they're going to learn your status anyway, and you want to make sure *you* do the telling.

## THE FAMILY

Because your family can't be picked like friends, coming out to them may be especially stressful. There are advantages and disadvantages.

For TPA member Stephen Jeffries, telling his parents was a godsend. His father and stepmother convened a family gathering to brainstorm ways to provide appropriate support. "My father was very supportive," Stephen says, adding that his is a large, Southern, conservative, Catholic family.

In the largest study on disclosure ever conducted, Robert Hays and colleagues at the University of California/San Francisco surveyed 165 HIV-positive gay men about disclosing their HIV status. Not surprisingly, Hays found that friends and lovers were rated as more supportive and responded more helpfully than relatives and colleagues. Among all the categories of people in a gay man's support network, disclosing only to mothers and fathers was found to increase rather than decrease depression and anxiety.

The reason, according to Hays, is parental overconcern. "Receiving a considerable amount of help from parents may damage egos and reduce self-esteem." Hays concludes that people with HIV can have better relationships with their parents if they teach the parents not to offer support that unintentionally treats their children as "victims."

## EARLY OR LATE?

In his study, Hays notes that AIDS activists have urged people with HIV to come out publicly as a means of personalizing the epidemic and decreasing stigma and stereotypes. As political as the epidemic is, however, think carefully before letting external pressure influence your decision.

Many people let the condition of their health determine when they disclose. "For as long as I appear healthy, I don't want to be treated any differently," says a man Hays interviewed. "To be given too much sympathy at this point would be depressing."

Balancing that viewpoint is the supportive role that friends, lovers, and family can play in long-term planning if they know your status early and, like yourself, have time to adjust to the news. Also, the thought of adding the stress of disclosure when already ill prompts many people to break the news while they're healthy and relatively stable emotionally and physically. Disclosing your HIV status to friends and family can cause more problems than it solves or it can provide an indispensable network of love and support. You'll want to take great care in making the decision to whom and when to disclose.

For many people, however, living with HIV is too big a secret to keep from the people they love. As Stephen put it, "The risk is worth it if you're willing to love yourself enough to try."

AIDS Survival Project has peer counselors, who are themselves living with HIV, who can be a big help when you are thinking about telling your loved ones that you are HIV positive. We've all been there and know what you're going through. Call 404-874-7926 or stop by 828 W. Peachtree Street, Suite 206.

# COMING OUT TO LOVED ONES [10]

## DO'S

✔ Do talk with a friend or counselor for advice on how to approach your family. Friends who've gone through the same process are especially helpful and can offer insights about specific individuals whom they've told and whom you both know.

✔ Do decide what level of control you want over who knows your HIV status. Unless you specifically tell a friend or family member not to tell others, they may mistakenly take your candor with them as a sign of general openness.

✔ Do choose carefully who you want to tell, not who you need to tell. You have no obligation but to yourself.

✔ Do read up on your basic HIV information. Friends and family who know little about the epidemic may entertain a multitude of misconceptions and myths about how HIV is transmitted and how quickly disease progresses.

✔ Do bring with you newsletters, books, brochures, videos, and phone numbers. Your family in particular may not know how to access such resources on their own.

✔ Do be in a position of confidence. If you haven't yet come to terms with your own HIV status, you'll have a hard time helping your loved ones do so.

## DON'TS

✖ Don't expect too much from them too quickly. While you want the support of your family in the long run, don't shut the door on people whose initial reaction to your infection is based on ignorance or fear. Educating them may take some time, but the result will probably be well worth it.

✖ Don't tell them when you're sick. Although bedside confessions are sometimes unavoidable, everyone, including you, will probably have an easier time if you tell them from a position of strength.

✖ Don't forget that "you can choose your friends but not your family." If a friend reacts negatively, you can find another. You may have to educate your family.

✖ Don't think it necessarily gets any easier after the first time. While the news may become "old hat" to you, people hearing it for the first time may react much the same way.

✖ Don't assume a specific reaction to your disclosure. While you may think you can anticipate a close friend or relative's reaction, overly specific expectations may leave you unprepared to deal with how they actually take the news.

# PLAIN TALK ABOUT HANDLING STRESS [11]

Stress negatively affects your immune system. However, it is next to impossible to eliminate all stress from your life. When stress occurs, it is important to recognize and deal with it. Here are some suggestions for ways to handle stress. As you begin to understand more about how stress affects you as an individual, you will come up with your own ideas of helping to ease the tensions and adapt to new situations.

### TRY PHYSICAL ACTIVITY.

When you are nervous, angry, or upset, release the pressure through exercise or physical activity. Running, walking, playing tennis, or working in your garden are just some of the activities you might try. Physical exercise will relieve that "up tight" feeling, relax you, and turn the frowns into smiles. Remember, your body and your mind work together.

### SHARE YOUR STRESS.

It helps to talk to someone about your concerns and worries. Perhaps a friend, family member, teacher, or counselor can help you see your problem in a different light. If you feel your problem is serious, you might seek professional help from a psychologist, psychiatrist, or social worker. Knowing when to ask for help may avoid more serious problems later.

### KNOW YOUR LIMITS.

If a problem is beyond your control and cannot be changed at the moment, don't fight the situation. Learn to accept what is, for now, until such time when you can change it.

### TAKE CARE OF YOURSELF.

You are special. Get enough rest and eat well. If you are irritable and tense from lack of sleep or if you are not eating correctly, you will have less ability to deal with stressful situations. If stress repeatedly keeps you from sleeping, you should ask your doctor for help.

### MAKE TIME FOR FUN.

Schedule time for both work and recreation. Play can be just as important to your well being as work; you need a break from your daily routine to just relax and have fun.

### BE A PARTICIPANT.

One way to keep from getting bored, sad, and lonely is to go where it's all happening. Sitting alone can make you feel frustrated. Instead of feeling sorry for yourself, get involved and become a participant. Offer your services in neighborhood or volunteer organizations. Help yourself by helping other people. Get involved in the world and the people around you, and you'll find they will be attracted to you. You're on your way to making new friends and enjoying new activities.

## CHECK OFF YOUR TASKS.

Trying to take care of everything at once can seem overwhelming, and, as a result, you may not accomplish anything. Instead, list what tasks you have to do, then do one at a time, checking them off as they're completed. Give priority to the most important ones and do those first.

## MUST YOU ALWAYS BE RIGHT?

Do other people upset you particularly when they don't do things your way? Try cooperation instead of confrontation; it's better than fighting and always being "right." A little give and take on both sides will reduce the strain and make you both feel more comfortable.

## IT'S OK TO CRY.

A good cry can be a healthy way to bring relief to your anxiety, and it might even prevent a headache or other physical consequence. Take some deep breaths; they also release tension.

## CREATE A QUIET SCENE.

You can't always run away, but you can "dream the impossible dream." A quiet country scene painted mentally, or on canvas, can take you out of the turmoil of a stressful situation. Change the scene by reading a good book or playing beautiful music to create a sense of peace and tranquillity.

## AVOID SELF MEDICATION.

Although you can use drugs to relieve stress temporarily, drugs do not remove the conditions that caused the stress in the first place. Drugs, may be habit-forming and create more stress than they take away. They should be taken only on the advice of your doctor.

# MORE ON HANDLING STRESS [12]

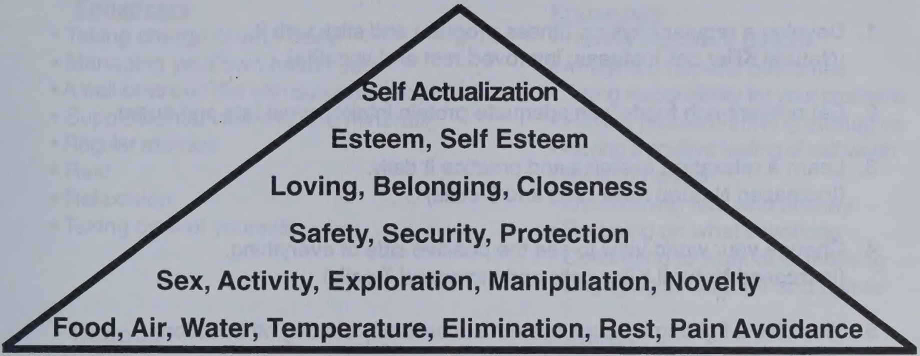
Stress is with us always. It comes from mental or emotional activity and physical activity. It is unique and personal to each of us. So personal, in fact, that what may be relaxing to one person may be stressful to another. For example, if you're a busy executive who likes to keep busy all the time, "taking it easy" at the beach on a beautiful day may feel extremely frustrating, nonproductive, and upsetting. You may be emotionally distressed from "doing nothing." Too much emotional stress can cause physical illness such as high blood pressure, ulcers, or even heart disease; physical stress from work or exercise is not likely to cause such ailments. The truth is that physical exercise can help you to relax and to handle your mental or emotional stress.

Hans Selye, M.D., a recognized expert in the field, has defined stress as a "nonspecific response of the body to a demand." The important issue is learning how our bodies respond to these demands. When stress becomes prolonged or particularly frustrating, it can become harmful—causing distress or maladaptation. Recognizing the early signs of distress and then doing something about them can make an important difference in the quality of your life, and may actually influence your survival.

To use stress in a positive way and prevent it from becoming distress, you should become aware of your own reactions to stressful events. The body responds to stress by going through three stages: (I) alarm, (2) resistance, and (3) exhaustion.

Let's take the example of a typical commuter in rush hour traffic. If a car suddenly pulls out in front of him, his initial alarm reaction may include fear of an accident, anger at the driver who committed the action, and general frustration. His body may respond in the alarm stage by releasing hormones into the bloodstream which cause his face to flush, perspiration to form, his stomach to have a sinking feeling, and his arms and legs to tighten. The next stage is resistance, in which the body repairs damage caused by the stress. If the stress of driving continues with repeated close calls or traffic jams, however, his body will not have time to make repairs. He may become so conditioned to expect potential problems when he drives that he tightens up at the beginning of each commuting day. Eventually, he may even develop one of the diseases of stress, such as migraine headaches, high blood pressure, backaches, or insomnia. While it is impossible to live completely free of stress and distress, it is possible to prevent some distress and to minimize its impact when it can't be avoided.

A man named Maslow developed a kind of pyramid of basic needs. If the needs at the bottom of the pyramid are not being meet well it becomes difficult to satisfy needs that are higher up on the pyramid. Many of the concepts and ideas we have looked at so far are pretty high on that pyramid and it is easy for us to assume ( this is the ASS of U and ME assume) that these simpler needs are being meet. If you don't feel safe you don't have a chance of building intimate relationships. If you're not eating well all the medication in the world is not going to boost your immune system. You may want to cut out this pyramid and tape it to the fridge to remind you to take care of the little things and the big things will take care of themselves in some ways.


Self Actualization
Esteem, Self Esteem
Loving, Belonging, Closeness
Safety, Security, Protection
Sex, Activity, Exploration, Manipulation, Novelty
Food, Air, Water, Temperature, Elimination, Rest, Pain Avoidance

MASLOW'S PYRAMID OF BASIC NEEDS

# STRATEGIES FOR NATURALLY ENHANCING IMMUNE FUNCTIONING[13]

1. Develop a regular physical fitness program and stick with it.
   (Natural Killer cell increase; improved rest and appetite)

2. Eat nutrient-rich foods with adequate protein intake; avoid fats and sugar.

3. Learn a relaxation exercise and practice it daily.
   (Increased Natural Killer cells and T-cells)

4. Change your world view to see the positive side of everything.
   (Increased Natural Killer cells and increased T-cells)

5. Visualize a fighting immune system successfully beating off infections.
   (Increased T-cells)

6. Learn strategies for overcoming fear and anxiety.
   (Protection against lowered levels of Natural Killer cells, suppressed interferon, reduced T-cells, B-cells, and salivary immunoglobulin A)

7. Let go of anger and unforgiveness.
   (Protection against reduction in Natural Killer cells and interferon)

8. Work to develop or maintain close, caring relationships.
   (Increased B-cells and T-cells)

9. Participate in a support group.
   (Increased Natural Killer cells)

10. Do loving things for other people.
    (Increased T-cells)

11. Develop a relationship with God.
    (Reduced stress; protection against lowered levels of Natural Killer cells, reduced T-cells and B-cells)

12. Pray and asked to be prayed for.
    (Quicker recovery, fewer complications, increased T-cells, B-cells, and Natural Killer cells)

13. Experience humor and create opportunities for joy and laughter.
    (Relief from depression; increased IgA antibodies)

14. Experience nature, art and music often.
    (Reduced depression; Increased T-cells and Natural Killer cells)

# MODEL FOR IMMUNE ENHANCEMENT

## PHYSICAL

### Enhancers

- Taking charge of your body
- Managing your own health care
- A well-balanced diet with adequate protein
- Supplemental vitamins and minerals
- Regular exercise
- Rest
- Relaxation
- Taking care of yourself

### Hazards

- Not believing you can influence your body
- Giving up control of your health care
- Eating junk food
- Eating a high fat diet
- Being a "couch potato"
- Not getting adequate rest and relaxation
- Smoking
- Drinking
- Taking inappropriate drugs

## PSYCHOLOGICAL

### Enhancers

- Having a positive outlook
- Imagining hopeful outcomes
- Taking responsibility for your problems
- Having problem-solving strategies
- Having a positive feeling of self-worth
- Avoiding anger
- Overcoming fear and anxiety
- Focusing on what's working
- Continuing to work at something
- Engaging in laughter and humor

### Hazards

- Having a negative, pessimistic outlook
- Being hopeless
- Blaming others
- Seeing problems as catastrophes
- Feeling bad about one's self
- Becoming angry
- Giving in to fear and anxiety
- Focusing on symptoms/what's wrong
- Not engaging in some type of work
- Having no laughter and humor

## SPIRITUAL

### Enhancers

- Having a personal relationship with God
- Seeing God as loving, caring, and forgiving
- Having close, loving, caring relationships
- Practicing forgiveness
- Prayer and meditation
- Experiencing beauty, nature, music and art
- Experiencing joy, thankfulness, and celebrations
- Having trust and faith in God

### Hazards

- Not having a personal relationship with God
- Seeing God as distant, angry, and not loving you
- Loneliness, no close, caring relationships
- Holding on to hurts, anger, unforgiveness
- Not experiencing beauty, nature, music and art
- Not allowing yourself to see things to be thankful for, or not engaging in joyful celebrations
- Not having faith or trust in God

# A MODEL FOR IMMUNE HARDINESS [14]

There has been a lot of research in the areas of stress management and dealing with psychological and emotional issues. The following article is an overview of many different research projects. Although much of this research was not done specifically about living with HIV the concepts it reviews are important for people living with HIV.

## INTRODUCTION

There has been extensive research in the last twenty years in the areas of stress, wellness, mind-body relationships, and immune functioning. While each of these studies has contributed in valuable ways to specific areas of research, some of the most exciting possibilities occur when the studies are looked at together. Collectively these data offer a model that may provide important assistance in the treatment of HIV.

While significant progress is being made in developing strategies to fight opportunistic infections, and some breakthroughs are occurring in combating the virus itself, the third strategy that is valuable to examine is that of immune enhancement. Little work has been done in this area with AIDS, though the field of psychoimmunology is rapidly gaining prominence in medical research. Reports indicate that AIDS appears to be a disease that is particularly amenable to a psychoimmunologic approach. Psychoimmunology refers to psychological influences such as experience, stress, emotions, traits, and coping on immune function and on the onset and course of immunologically resisted or mediated diseases. The purpose of this review is to combine pertinent research data in order to develop a model for natural immune enhancement.

## PHYSICAL

There are a number of physical factors that are important in immune system functioning. Each contributes to the important role of physically taking care of one's self in a way that enhances immune health. A basic requirement is that individuals see themselves in control of their physical functioning. Long-term survivors of AIDS take personal responsibility for their health and believe they can influence the outcomes. Long-term survivors were sensitive to their bodies and their physical and psychological needs.

Taking responsibility for one's health involves several key areas: diet, exercise, rest and relaxation, and self-nurturing.

Failure to absorb adequate nutrients is a major problem for people with AIDS. Consequently diet becomes especially important in assuring immune health. Adequate protein, vitamins and minerals are necessary for healthy immune functioning, along with adequate calories to assure appropriate body weight .

Studies of long-term AIDS survivors have found that one of their characteristics is having a regular physical fitness program . Profound enhancement of Natural Killer cell activity post exercise has been reported. Studies have found that increased physical fitness appears to be a way of moderating the impact of stressful life events and that a regular physical fitness program may be an important component of preventing illness. Adequate exercise has long been implicated in enhanced cardiovascular functioning, respiratory health, appetite enhancement and improved sleeping. It appears that it may also be a very important part of immune enhancement for people with HIV.

Rest and relaxation are very important when the immune system is in the process of battling disease. Study results suggest that anything that interferes with a normal sleep pattern can add to immune risk. Rest and relaxation is an important component of the healing process. Individuals who were long-term survivors of AIDS were more likely to be individuals who engaged in some type of self-nurturing activity and were also able to be assertive and say "no" when they needed to. Smoking, alcohol, and drug use have all been found to interfere with healthy immune functioning.

From a physical perspective, there are several key areas to support immune health, a well-balanced diet which assures adequate protein, vitamins and minerals; a regular exercise program; solid rest and relaxation; and a decision to do self-nurturing that includes avoidance of smoking, alcohol, and drugs.

## PSYCHOLOGICAL

Since the early days of stress research, there has been a growing awareness that a person's thought processes have a significant influence on their physical functioning, particularly their immune functioning. Research has, in fact, shown that it is not the actual stress persons are under that influences their well-being. Instead it is their perception of the level of stress that actually determines how the body will react.

Because perception is so important, learning to select the best perception can be a critical variable in assuring healthy immune functioning. The results of a recent study indicated greatly enhanced immune functioning when individuals changed their world view: In the study group there was an average increase of 53% in the various health protecting immune components. This ranged from an increase in Natural Killer cells of up to 30% to increased T-cell counts of up to 200%. The perception of control over your circumstances has been found to be an important variable in stress-related illness. People who are more likely to get sick tend to feel powerless in the face of overwhelming forces.

Studies of AIDS patients at the University of California at San Francisco found that AIDS patients with pneumocystis pneumonia had a higher survival rate when they had a greater sense of control over their lives and destinies. Those who lived the longest saw the physician as collaborator with them, rather than seeing the physician as someone they dealt with in a passive compliant manner, or in a defiant, adversarial way. Long-term survivors of AIDS were found typically to be individuals who take responsibility and control over their own circumstances Individuals with pneumocystis pneumonia who were long-term survivors of AIDS had the ability to view problems in a positive way and to believe they had control over them. Individuals with a chronic negative attitude have been found to have lower levels of T-cells and Natural Killer cells.

Life stress in the form of anxiety was found to result in lowered immune functioning and poorer surgical outcomes. This study suggests that just the anxiety created by medical procedures can create serious immune risk. The authors recommend that taking time to do everything possible to relieve anxiety before a medical procedure is an extremely important medical intervention. The frequency of hospitalizations, surgery, and medical procedures with AIDS patients may be contributing to the risks of an already suppressed immune system. Another important variable in stress-related illness is being able to handle the challenge of a serious illness. Those most likely to survive a life-threatening illness interpreted potentially stressful events as challenges to be met with expected success.

Similar to fear and anxiety, anger and bitterness are dangerous to immune health. Longitudinal studies of physician health have found that hostile, cynical individuals are more likely to encounter a high degree of illness. Anger seriously affects the immune system. Studies have found a correlation between anger and reduced levels of interferon and Natural Killer cells found evidence that individuals who spend much of their day feeling angry and hostile have poorer immune functioning. Hostility, depression, and overall anxiety associated with general life stresses have been found to correlate with a reduction in T-cells.

Another important psychological area that has not been carefully considered for its potential immune risk in people with AIDS is the effect of job loss. Studies have looked at women who had been unemployed, tracing their immune status over a period of months. They found that unemployment of over nine months duration is accompanied by a decrease in lymphocyte activity to PHA and PPD which function to stimulate helper T-cells. They found that long-term unemployment tended to cause feelings of anxiety, depression, and hopelessness, all of which have been implicated in decreased immune health.

Those individuals who tended to view their symptoms as intense, noxious, and disturbing experienced greater overall discomfort. They also experienced greater social and vocational disability. Learning to refocus and view one's body from a positive, "what's working" perspective may be an important tool to reduce the focus on symptoms. Focusing on symptoms leads to becoming increasingly isolated, depressed, and unable to work. Higher mortality rates were found among a group being treated at home when they exhibited preoccupation with complaints. This group also demonstrated a tendency to see themselves as worthless, unpleasant and undeserving and to be downhearted, despondent, and pessimistic.

Changing a person's feelings of self-worth, hopefulness, and control have been found to change the biochemical balance associated with depression. Cognitive therapy in which people were taught new ways of viewing their situation in many instances has proved even more effective than anti-depressive drugs.

Hearty laughter has been found to increase the levels of endorphins and enkephalins in the brain. This is a natural way of producing the body's opiates, which work to counteract depression. Studies have found that focusing on something funny significantly increases the number of IgA antibodies, an important component of immune functioning. People who use humor as a coping mechanism have been found to have higher concentrations of these antibodies. Norman Cousins, in his famous self-experiments even demonstrated the ability to cure himself of a serious disease on two different occasions through using humor.

This survey of attitudinal research suggests that a very important component of immune system functioning lies in an individual's psychological well-being. Specific outlooks and thought processes are crucial to immune health: keeping a positive outlook on life; imagining positive, hopeful outcomes; taking responsibility for problems; developing problem-solving strategies; having a positive feeling of self-worth; avoiding anger, anxiety and fear; focusing on what's working instead of each symptom; staying employed if at all possible; and use of laughter and humor as coping mechanisms. All of these factors are important psychological strategies in maximizing immune health.

## SPIRITUAL

A third area that has not previously been dealt with very extensively in the literature is that of spiritual factors which influence health and immune functioning. The term "spiritual" has different connotations for different people. Because this is an area less frequently addressed, it warrants definitions and clarity in order to explain the meaning of the term "spiritual" and to differentiate positive characteristics from negative characteristics.

Research has shown a high correlation between healthy immune functioning and characteristics usually associated with spiritual well-being. It is important in examining this area first to differentiate spiritual well-being from simply being involved in religious activities. There has been extensive research examining spiritual and religious functioning in people's lives. The two primary categories identified were "extrinsic religious orientation" and "intrinsic religious orientation."

Individuals with an extrinsic religious orientation have been found to use religion as a means to accomplish their own ends. It tends primarily to benefit them in some way, usually in the form of security, solace, social contacts, distraction, a sense of self-righteousness or self-justification. Their religious creed is viewed by them as not particularly important, and they tend to bend it or interpret it in a way that meets their personal needs. This group has been described as turning to God but without turning away from self. Extrinsics are more likely to view God as abstract, distant, impersonal, and uninvolved in human affairs. They are less likely to have mystical spiritual experiences. They have been described as being closed-minded and inflexible thinkers.

Research has shown extrinsics to be more likely than other groups to cheat and then to find ways to rationalize it. They have been found to have high levels of prejudice. This group is also more likely to have an intolerance for people with AIDS. While extrinsic religious orientation can be found among most religious groups and denominations, research has shown that they are more likely to be found among those who are legalistic, non-Christian, or who focus on good works as the path to assuring eternal well-being. An extrinsic religious orientation is considered by researchers to be indicative of an underdeveloped, unhealthy spiritual status.

The other primary group identified were those who have an intrinsic religious orientation. This group is considered to exhibit healthy, mature spiritual well-being. This group has been found to have a high level of motivation around their belief system. Having accepted a religious creed, they try to understand it and live it fully, with their personal needs seen as less important. This group is likely to experience God as warm, close, personal, and very much a part of daily life. They are also more likely to have mystical religious experiences.

Research has found this group is likely to be non-prejudiced. Intrinsics are found in every religious group and denomination. They are more likely, however, to be Christian, and to believe that God loves everyone and desires a relationship with them, and they desire to share that information with others.

Characteristics consistent with healthy immune functioning have been found across a number of studies to correlate with intrinsic religious orientation. Conversely, studies have shown that those with an extrinsic religious orientation are more likely to exhibit characteristics that are hazardous to healthy immune functioning.

A major attribute of spirituality is love—love of others as well as love of God. Studies have shown that individuals who have close, caring, confiding relationships have significantly higher immune functioning. Conversely, those who are lonely and without loving relationships have been found to have lower levels of Natural Killer cells. Individuals who have recently lost an important loving relationship had significantly reduced levels of B-cells and T-cells. In one study, individuals who participated in a support group had higher levels of Natural Killer cells than those who did not participate. Long-term AIDS survivors were more likely to have supportive contact with others with AIDS. Having close, loving, caring relationships appears to be important in healthy immune functioning, while loneliness is implicated in reduced immune health.

One study looked at loneliness from a spiritual perspective. The investigators found that individuals who had a negative image of God were more likely to be lonely. This research suggested that a negative image of God prohibits the development of a personal relationship with God. Also, having a negative image of how they were perceived by God resulted in individuals who exhibited poor self-esteem. This makes one less likely to attempt to venture out and join new groups or try to make new relationships to relieve loneliness. Those individuals who did not experience significant loneliness experienced God as supportive, helpful, and caring, and they saw God as loving them. They tended to be open to mystical experiences and were actively involved in trying to live according to Christian principles.

Individuals who reported a relationship with God were likely to be more optimistic, extroverted, and better able to relate to their family than were those who did not report a relationship with God. Lovingly caring about others is another important characteristic found to increase T-cell counts. Individuals who have developed a high level of spiritual well-being are less likely to be self-centered and more likely to care about others. Long-term AIDS survivors have been found to be more likely to be altruistically involved with other people and to have a new sense of meaning and purpose in their lives in spite of their disease.

A reported relationship with a loving God has also been found to assist in a number of areas already implicated as important in enhancing immune functioning. Individuals with healthy spirituality as characterized by an intrinsic religious focus had a greater sense of control over their lives and higher interpersonal trust. Characteristics of emotional well-being have been observed in persons with an intrinsic religious orientation and they tend to have a higher levels of confidence and emotional sensitivity. Extrinsics had a tendency to feel powerless and helpless. Those individuals who have characteristics of spiritual well-being and see themselves as collaborating with God in making life decisions are most likely to have a high sense of control.

High levels of stress associated with bereavement have been found to result in depressed immune functioning with increased morbidity and mortality. Researchers have found that individuals who were experiencing bereavement and high periods of challenging life events (as is common in many people with AIDS) had much lower levels of stress when they had the “spiritual support of a relationship with God”. The characteristics of their relationship with God included: reports of experiencing God’s love and caring on a regular basis; reporting a close, personal relationship with God; and using faith as central to their coping strategies.

Prayer and meditation are considered to be methods used to communicate with God. Research has shown that different types of prayer also correlate with immune enhancing states of well-being. Prayer appears to be a widely recognized source of spiritual well-being. A recent Gallup survey revealed that a representative 84% of the American people believe that God is a heavenly father who can be reached by prayer. Individuals who pray have been found to exhibit lower levels of stress and higher levels of immune functioning. Persons who felt they had spiritual experiences when they prayed were more likely to show high scores on all quality of life items measured. Meditative prayer (feeling or being in the presence of God; thinking about God; listening for God; and worshipping God) was correlated with an overall sense of well-being and religious satisfaction. Colloquial prayer (conversational requests for guidance, blessings, forgiveness, and expressions of love) was positively correlated with happiness. Ritual prayer (reciting from memory or a prayer book) was positively correlated with relief from sadness, loneliness, tension and fear. Petitionary prayer, however, (asking for material things for self and others) was not correlated with any area of well-being.

A very important component of spiritual well-being is the area of forgiveness. Researchers have reported that asking others and God for forgiveness is a critical component of the healing from any illness. Forgiveness represents the spiritual/psychological antidote for anger and bitterness that result in reduced levels of interferon, T-cells, and Natural Killer cells reported beneficial impact on physiological processes and cardiovascular status when individuals came to terms with forgiving themselves and others, in addition to developing emotionally healthy self-concepts and giving unselfishly to others.

Being in the presence of beauty, art, music and nature add to spiritual well-being and are implicated in health and healing. This can be extremely valuable in reducing depression and keeping a positive outlook, both of which are important in healthy immune functioning. In studies of recovery from surgery, individuals who had a window where they could see a beautiful nature scene spent less time in the hospital after surgery, required less pain medication, and had fewer infections and complications than did a matched group whose window looked out on a brick wall.

Joy and celebration are spiritually uplifting activities that have been implicated in healthy immune functioning. Individuals who engage in humor and in joyful celebration have been found to have higher levels of IgA antibodies. In addition, laughter, joy, and celebration are important in reducing or preventing depression.

Finally, faith in God plays an important role in the healing process. Individuals who had adequate faith to turn their disease over to God were reported to be more likely to experience healing. Faith in God has also been found to result in lower levels of stress and anxiety among those experiencing life-threatening illnesses. Stress and anxiety have previously been implicated in reduced immune functioning.

Much that is required for enhanced immune functioning requires making changes in one's life and world view. Difficult life changes have also been reported as being easier when an individual has established a relationship with God. In studies of drug users, those individuals who experienced the development of an intrinsic committed faith, seeing God as loving and forgiving, reported extra strength to resist the temptation of reverting to drugs. Studies of prisoners found that those who developed a personal relationship with God while in prison were less likely to commit crimes that returned them to prison than were other prisoners who had not developed a relationship with God.

Overall, it appears that healthy spiritual well-being, including: a personal trusting relationship with a loving, caring, forgiving God and integrating spiritual principles of love, caring for others, forgiveness, prayer, beauty, art, music, nature, and joyful celebration into daily living provide valuable potential for enhanced immune functioning. In addition, they are consistently indicated as important parts of an overall high quality of life.

## Conclusion

There are a number of behavioral characteristics that can be utilized to enhance overall immune functioning. By integrating these components of healthy physical, psychological, and spiritual functioning into the daily lives of those who are HIV positive, there is already strong research data that would support the likelihood of enhanced immune functioning as well as quality of life. This model also provides an excellent framework for researching the long-term outcomes of those who successfully manage to live within this framework. This total area of immune enhancement provides some extremely exciting possibilities for combating HIV infection.

# FOOTNOTES

1 From the book self esteem 1970, 1975 Virginia Satir Published by Celestial Arts, Milbrae, CA

2 Based on the writings of Roy Griffin, the creator of Operation: Survive!

3 by Christopher D. L. Miller, 1994

4 by Jim Lewis and Michael Slocum

5 by Joe Wheeler, 1994. Source: MountainBrook Foundation

6 by Joe Wheeler, 1994. Source: MountainBrook Foundation

7 by Christopher D. L. Miller, 1994

8 by Christopher D. L. Miller, 1994

9 by David Thomas, reprinted from *Positively Aware*, Fall 1993

10 from *Positively Aware*, Fall 1993. Special thanks to TPA member Stephen Jeffries, who helped compile this list

11 by Louis E. Kopolow, M.D. from *Positively Aware*, Fall 1993

12 by Christopher D. L. Miller, 1994

13 Developed by TOTAL WELL-BEING, Atlanta, GA

14 by Melanie Adair, M.A; N. Kortner Nygard,Ph.D.; Joe B. Adair, Ph.D.; and R. Wayne Maddox, M.S.W.

# GOVERNMENT ASSISTANCE

# UNDERSTANDING MEDICARE [1]

## WHAT IS MEDICARE?

Medicare is a health care program provided by the federal government. It is for people who are on Social Security because they are elderly, over 65 years of age. It is also offered to persons who are on Social Security because they are disabled.

## WHEN WILL I RECEIVE MEDICARE?

You are eligible for Medicare after you have been receiving a Social Security Disability check for 2 years. That is 29 months after you were first found to be disabled, the 5 month waiting period and 2 years.

There is only one exception to this rule. Individuals with end-stage renal (kidney) disease are eligible for Medicare after being disabled for three months. All others, no matter what their disability, must wait the 29 months. About three months before you are eligible for Medicare you will receive a red/white/blue card in the mail that says "Health Insurance." This is Your Medicare card.

## WHAT WILL MEDICARE COST ME?

As of January 1, 1996, the monthly premium is $36.60. This will be deducted from your monthly Social Security check automatically, unless you tell them that you do not want Medicare. This is for Medicare Part B; it is an optional coverage. If you are hospitalized, your deductible will be $676 per spell of illness. This is under Medicare Part A, and all persons receive Medicare Part A automatically, at no cost.

## WHAT DOES MEDICARE COVER?

Medicare has two parts: Part A covers inpatient hospital services and services furnished by other health care providers, such as nursing homes, home health agencies and hospices. You must be sure that it is a Medicare-approved provider. That is, a provider who contracts with Medicare to accept payment.

Part B covers doctor's visits, some drugs but only if they are not self-administered, outpatient services, emergency room services, x-ray and lab tests, surgical dressings, durable medical equipment, prosthetic devices, and some ambulance services. This is not a complete list of covered expenses. For a specific question call AIDS Legal Project at 404-614-3969.

## WHAT IS NOT COVERED BY MEDICARE?

Medicare will not cover prescription drugs, glasses, hearing aids, most dental work, cosmetic surgery, routine foot care and orthopedic shoes, custodial care and homemaker service, unless it is part of hospice, and charges by immediate relatives or household members.

## WILL I HAVE TO SHARE THE COST OF CARE WITH MEDICARE?

Yes. For Medicare Part B there is a $100 deductible. After the first $100 Medicare will pay 80% of the approved Medicare charge. You will be responsible for the other 20%. As of January 1, 1996, Congress is seriously considering proposals to raise Medicare co-payments, so this may change.

Medicare may pay your health care provider directly or they may pay you. It is wise to ask if your provider accepts Medicare. If so, do they accept "assignment," which means that they agree to accept Medicare's payment as payment in full. Also ask if the provider bills Medicare directly.

# WHAT IS QUALIFIED MEDICARE BENEFICIARY (QMB)?

If your monthly Social Security Disability check is $601 or less, you may qualify for QMB. This is a program that will pay your monthly Medicare premium of $36.60. You will not have to pay the 20% co-payment or your deductibles, both the $100 and the hospital deductible. But you must be sure to go to a health care provider who accepts both Medicare and Medicaid.

Another program is called Specified Low Income Medicare Beneficiaries (SLMB) and this will help you if your income is between $601 and $660 a month. This will only pay your monthly Medicare premium of $36.60, there are no other benefits, but it will help you save nearly $40 every month!

To apply for either of these programs contact the Department of Family and Children Services (DFACS) in your county.

# STATE INSURANCE CONTINUATION PROGRAM [2]

The State of Georgia has a program to help people with HIV disease pay for their private health insurance. Most employers are required to continue your insurance for a specified period of time after termination of your employment. People with HIV who pay their own insurance premiums, either through a group or individual policy, and who do not have a lot of money, can get assistance from the State to pay these insurance premiums.

The Ryan White Project's office has money to pay your health insurance premiums if you meet certain guidelines:

1. You must be HIV positive.
2. You must live in Georgia.
3. You must be leaving or have lost your job.
4. You can't have more than $10,000 in liquid assets. Your house and car don't count, just things like cash, stocks, bank accounts.
5. A single person can make no more than $1,047 per month. If you have dependents, you can make more.
6. You must have insurance before the Ryan White Office starts to pay. They will not pay for any new policies.
7. You are ineligible if your employer pays your premium. If you have to pay all or part of your premium, you can be eligible only for the portion you pay.

   This program is available on a statewide basis and is administered by the county health departments.

To apply, bring proof of income (or lack of income), proof of assets, such as bank statements, proof of HIV status and a copy of your insurance premium bill to the health department of the county in which you reside or contact Libby Brown at the Ryan White Projects Office at 404-657-3100. For more information call the Atlanta Legal Aid Society's AIDS Legal Project at 404-614-3969.

**Forms you need to apply are located in Appendix A of this workbook.**

# DRUG REIMBURSEMENT PROGRAM [3]

This program provides antiretrovirals to low-income people with less than 500 T-4 Cells. People being seen by private physicians are eligible if income is less than 125% of the poverty level. For a single person this equates to an annual income of $8,275.

To apply for the program your physician should contact Ms. Libby Brown at 404-657-3100 at the Department of Human Resources' Ryan White Projects Office. This program is available on a statewide basis.

Forms you need to apply are located in Appendix B of this workbook.

# ADULT MEDICALLY NEEDY[4]

The Adult Medically Needy Program (AMN) is a Medicaid program operated by the Division of Family and Children Services (DFCS). The purpose of this program is to allow aged, blind or disabled persons whose incomes are too high for other Medicaid categories of eligibility to become eligible by deducting medical expenses from income. If countable income after deductions for incurred medical expenses falls below the Medically Needy Income Limit (MNIL) of $317 per month for an individual or $375 for a married couple, AMN eligibility is achieved.

Applicants must meet all other eligibility requirements, including the SSI resource requirements as there is no spenddown for resources. For example, Joe's monthly countable income is $500; however, he has $184 in unpaid medical expenses. When these unpaid bills are deducted from his income, Joe becomes income eligible to receive at least one month of Medicaid coverage.

DFCS has instituted several changes in the AMN program which became effective July 1996. These changes pertain to how eligibility is calculated. Under the **old** rules, eligibility for AMN was calculated over a three-month period. An applicant's countable income under SSI rules was estimated for the three-month period and three times the MNIL was subtracted from the estimated income figure to determine how much the applicant would have to spend on medical expenses before becoming eligible for Medicaid. The difference between a person's countable income and the MNIL is called the spenddown amount. Once incurred medical bills equaled the spenddown amount, an applicant was eligible for Medicaid to pay Medicaid covered medical bills incurred after the spenddown amount was reached.

Also, under the **old** rules, the AMN program applied to the three months prior to the month of eligibility. When Medicaid eligibility was determined and there were unpaid bills in any of the three prior months, then AMN eligibility was to be checked for each of the three months.

Under the **new** rules now in effect, a sixth-month review period has been created. Each of the six months of the review period is a separate budget period, and eligibility is determined for each month individually. The review period begins on the first day of the month in which the application is filed and runs through the last day of the sixth consecutive month. Under this new system, an applicant who meets the spenddown amount for one month will receive one month of Medicaid coverage. If he or she has two months worth of spenddown, then two months of Medicaid coverage will be extended and so forth. Overall eligibility reviewing the aged, blind or disabled criteria and resources will be evaluated every six months. For the three months prior, each month is also a separate budget period. When the spenddown is met, the applicant is considered spenddown eligible, and is approved for Medicaid effective the day spenddown is met.

**The following individuals' medical expenses can be used in meeting the spenddown:**

- the applicant.
- the applicant's legal, ineligible spouse.
- the applicant's non-legal, ineligible spouse only if the second potential spenddown is used as the AMN spenddown.
- the applicant's ineligible child.

- the applicant's ineligible parent if the applicant is a child.
- the deceased spouse or child of the applicant if the applicant remains liable for payment of the bill.
- the child of the applicant who has reached 18 years of age if the child was under 18 at the time the medical expense was incurred and the applicant remains liable for the bill.

**Medical expenses are used to meet the spenddown if they meet all of the following conditions:**

- The bill is unpaid as of the first day of the month, or is incurred or paid during the budget period.
- The applicant is legally obligated to pay the expenses of the people in the above list.
- There is no third party resource that is liable for payment of the bill.
- The bill is medically necessary. Any expense ordered or prescribed in writing by a medical practitioner recognized under state law is medically necessary. Doctor and hospital services are considered medically necessary.

The spenddown may be met by using medical expenses incurred prior to the month of application. If this occurs, the applicant is eligible for Medicaid from the first day of the month. If the spenddown is not met by previously incurred bills, the case is placed in suspense until enough bills are incurred to meet the spenddown.

An applicant may use virtually any kind of medical bill to meet the spenddown amount. The definition of a medical bill is broad and includes such things as loans and credit card charges to pay for medical expenses. Medical bills include amounts incurred for medical insurance premium payments and coinsurance and deductible amounts which remain unused after the insurance coverage is used. Examples of medical expenses include services provided by chiropractors, dentists, opticians, sitters, doctors, etc.; medical care purchases; prescription drugs and over-the-counter medical needs; transportation cost to obtain medical services (allow 21¢ per mile or actual cost, whichever is less); and medically necessary ambulance service. Medical bills with non-Medicaid providers can be used to meet spenddown, but the Medicaid program will only make payments to Medicaid-certified providers.

The above information is general and is not intended to be legal advice. For information about your specific situation, you should contact your county DFCS office, a case manager, a social service agency, the AIDS Legal Project, or a private attorney.

# DOCUMENTATION REQUIRED WHEN APPLYING FOR BENEFITS

## IDENTIFICATION

One type of identification for every family member.

**Examples:**

| | | |
|---|---|---|
| Georgia Drivers License | Food Stamp ID | Georgia ID card |
| School Records | Birth Certificate | Any personal ID |

## RELATIONSHIP

Documents or ID's showing relationship for every family member:

**Examples:**

Marriage license
Baptismal Certificate
Birth Certificates
Divorce Decree
Guardianship or Adoption Papers

## SOCIAL SECURITY CARD

Bring a Social Security Card for every member who has one.

## RESIDENCE VERIFICATION

One type of residence verification which shows both your name and address.

**Examples:**

- Recent electric, water or phone bill
- Voter registration card
- Current drivers license
- Recent rent or mortgage receipt

## INCOME VERIFICATION

You will be required to provide documentation of income for yourself and possibly other family members.

**Examples:**

- Pay stubs or earnings statement from employers
- Award letters from Social Security, VA, unemployment pensions, etc. A record of earnings from self employment

## STATEMENT OF SUPPORT

If someone has been providing support to you, a written statement must be obtained from that person and should include the following: Specify what kind of support has been provided (food, shelter, cash). If support was financial, the amount must be included and whether or not it was a loan. If support was room and board the address must be included. Specify exact date of when support was provided. Statement must be signed and dated by the person(s) who provided support and must include the address and telephone number of person(s) providing support.

## ASSET VERIFICATION

You will be required to provide current information and verification of assets.

**Examples:**

- Most recent bank statements
- Vehicle title or registration
- Mortgage statement showing balance owed
- Verification of stocks or bonds
- Property valuation information
- Bank statement showing balance owed
- Life insurance policies
- Certificates of deposit

## MEDICAL EXPENSES

You may be required to verify medical expenses, this may include both paid and unpaid bills.

**Examples:**

- Bills and receipts from doctors, hospitals, dentists, prescription drugs, lab and X-ray services, ambulance services, eyeglasses and medical insurance premiums.

## MEDICAL INSURANCE

Information should include the name, policy number, dates of coverage, and explanation of benefits.

**Examples:**

- Medicare or Medicaid card
- Health insurance card

# WANT TO INCREASE YOUR INCOME?[5]

Have you ever been in the position where there just wasn't enough money to go around? You say you are there right now? Well read on ....

The program I am talking about will not pay your Rich's bill or your fare to Key West for Easter, but it may increase your income. I am talking about the FOOD STAMP program. This is a federally funded and state operated welfare program. It can help people with low income or disabled people living on SSI or Social Security to increase their income.

Food stamps are government coupons that can be used like money to purchase food. Food stamps may not be used to purchase tobacco, alcohol, pet food, paper products, or cleaning supplies. You may qualify for food stamps if you meet the income and resource test. Special considerations are given to households with elderly or disabled individuals.

## MONTHLY GROSS INCOME LIMITS:

| Non-elderly/non-disabled: | | Elderly/disabled: | |
|---|---|---|---|
| **# In Household** | **Income** | **# In Household** | **Income** |
| 1 | $ 738 | 1 | $ 937 |
| 2 | $ 996 | 2 | $ 1264 |
| 3 | $ 1254 | 3 | $ 1591 |
| 4 | $ 1512 | 4 | $ 1919 |

To obtain food stamps your resources may not be over $2,000, or $3,000 for an elderly or disabled household. This does not include the home you live in or your car if it is valued at $4,500 or less. If your car is worth more than $4,500, a part of it will count toward your resource limit. Money in the bank, stocks, savings, etc. are generally considered resources, not your personal household items.

If you live with a non-relative, such as a roommate, friend, or partner then it is important to state that you **PURCHASE, STORE AND PREPARE YOUR FOOD SEPARATELY.** That way his/her income will not be counted against you. Generally if you live with your family the income of the entire household will be considered, and you may not be eligible unless someone in the household is elderly or disabled or has minor children.

You may file an application at the Department of Family and Children Services in your county. You will need two pieces of identification. A Social Security number is required and a second piece of ID such as a driver's license, Grady card, birth certificate, etc. Pieces of identification with your name, your address and picture are the most helpful. It is also necessary to bring proof of your current income, or expected income and proof of your rent and utilities. You have a right to apply the day you go to the office. This is important because food stamps are issued as of the day of application. BE SURE to at least sign and date the application the day you go to the office. You may also call and ask them to mail you an application.

If you are unable to go to the office, you may appoint someone to go for you. You should give them a note authorizing them to act on your behalf. They should bring proof of their identity as well as all the proof listed above to assist in filing an application on your behalf.

**If you are disabled** here are two additional tips. A disabled person can obtain more food stamps if the cost of his/her rent and utilities are greater than 50% of their income. A second way for a disabled person to receive more food stamps is to bring in all current medical bills that are not covered by insurance and Medicare premiums. Be sure to ask your pharmacist for a printout of your medication bill because these costs will be considered as well.

If you qualify for food stamps you should receive them within 30 days of application. However, if you are homeless or have less than $150 income and $100 in resources, or your monthly rent and utilities are more than your monthly gross income, you should get your food stamps in 5 days!

# MEDICAID 6

## Medicaid in the State of Georgia

Early in 1996 the Department of Medical Assistance (DMA) in Georgia notified Medicaid recipients that major changes would soon be taking place in the Medicaid program. These changes have been in the works for a number of years.

This is a pilot program, which means it is a program which will be tried out in a certain area, and, if successful, duplicated in other areas. The program here is modeled after programs in North Carolina, Florida and Kentucky, where contracts were set up with primary care physicians and other providers to deliver and coordinate health care.

The concept behind these programs is managed care. While the details are still being finalized, it appears that in many counties in the state of Georgia, if you are a Medicaid recipient you soon will be asked to choose between Georgia Better Health Care or a Health Maintenance Organization. Georgia Better Health Care (GBHC) is a managed care program developed by the DMA. *(See the Access to Healthcare chapter of this workbook for more about managed care).*

AIDS Survival Project will be monitoring developments in Georgia's Medicaid program. You can stay on top of this issue by calling AIDS Survival Project at (404)874-7926, reading the monthly *Survival News,* or calling the Medicaid hotline number at 1-800-246-2757.

## What Is Medicaid?

Medicaid is government health insurance for disabled and low-income persons. Authorized under Title XIX of the Social Security Act, Medicaid is a means-tested entitlement program financed by state and federal government and administered by the states. Federal guidelines place requirements on states for coverage of specific groups of people. States that meet the federal eligibility and benefit guidelines, receive federal matching payments based on the state's per capita income. The federal share ranges from 50 to 80 percent of Medicaid expenditures.

Because states establish their own financial eligibility criteria, there are large state to state variations in eligibility thresholds and coverage. For specifics about Georgia's eligibility requirements, call the Department of Medical Assistance at 404-656-4479.

## Who Is Covered By Medicaid?

Currently, 36 million people, or one in eight Americans, receive Medicaid; over half of Medicaid recipients are children. Low-income does not immediately qualify an individual for Medicaid. Only persons who fall into particular categories such as people receiving cash assistance or low-income children and pregnant women are eligible. The population receiving Medicaid assistance breaks out as follows:

- 3.7 million elderly persons
- 4.9 million blind and disabled persons
- 7.4 million adults and families
- 16.1 million children

## WHAT SERVICES ARE COVERED UNDER MEDICAID?

Medicaid covers a broad range of services. Because of the limited financial resources of people using Medicaid, few or no cost-sharing requirements are imposed. Some of the federally-mandated services are:

- inpatient and outpatient hospital care
- services of physician, midwife, and certified nurse practitioner
- nursing homes and home health care
- rural health clinics/federally qualified health centers

States have the option to cover additional services and still receive federal matching funds. Commonly offered optional services include prescription drugs, clinic services, prosthetic devices, hearing aids, and intermediate care facilities for the mentally retarded.

## WHAT DOES MEDICAID HELP PEOPLE LIVING WITH HIV AND AIDS?

People with HIV and AIDS depend heavily on Medicaid. Currently at least 40% of all people living with AIDS in this country and more than 90% of HIV-positive children access their health care through Medicaid. This program provides $3 billion annually to HIV-positive individuals, over six times more funding for AIDS care than the Ryan White CARE Act.

## WHERE CAN YOU FIND OUT MORE ABOUT MEDICAID?

To have your questions answered, call the AIDS Legal Project at (404) 614-3969.

# FOOTNOTES

1 from the AIDS Legal Project, a program of Atlanta Legal Aid Society

2 by Chip Rowan, Attorney At Law, Koval & Rowan

3 by Alicia A. Culver, 1994

4 by Sylvia B. Caley, AIDS Legal Project, a program of Atlanta Legal Aid Society

5 by Mary Jane Lubinski, Living Room

6 Excerpted from an article by Alicia A. Culver, *Survival News,* January 1995

# NOTES

# LEGAL ISSUES

# LEGAL TOOLS FOR SELF EMPOWERMENT

## PREFACE

Persons with HIV disease and their loved ones often face daunting problems such as employment discrimination, loss of health insurance or other benefits, problems with housing, and concerns about how to plan for the future. If you know your legal rights, however, the law can be an important and necessary tool for self-empowerment.

This section summarizes the rights of people with HIV with respect to employment, health insurance, financial planning, housing and wills and powers of attorney. This section is not intended to provide legal advice to you with a particular problem. It is for information only. If you have specific legal concerns, you should consult an attorney.

# PEOPLE WITH HIV HAVE A RIGHT TO WORK

## THE AMERICANS WITH DISABILITIES ACT (ADA)

One of the most common worries for people living with HIV is discrimination in the workplace. Many people are afraid that they will lose their jobs and benefits if their employers learn that they have HIV.

You should know that there are strong laws that protect people with HIV from job discrimination. If you can perform the essential functions of your job and if your employer employs 15 or more workers, you are protected under federal laws preventing discrimination.

The Americans with Disabilities Act ("ADA") is the most sweeping anti-discrimination law on the books for people with HIV disease. While it is not the only law that may prohibit discrimination, it is the most comprehensive.

The ADA provides that it is unlawful for an employer to refuse to hire, to fire, or to otherwise discriminate against an individual with HIV disease if that individual can perform the essential functions of his or her job. It also provides that an employer cannot discriminate against persons with HIV disease in any other privilege of employment, including fringe benefits.

Not only does the ADA prohibit discrimination against persons with HIV, it requires an employer to take affirmative steps to accommodate workers with disabilities, including HIV. In other words, an employer may be required to offer a worker flexible hours, job restructuring, extra unpaid medical leave or other accommodations.

If a person with HIV has been discriminated against in violation of the ADA, he or she can sue the employer in federal court. If he or she proves that the discrimination occurred because of his or her HIV status, s/he may be entitled to reinstatement, restoration of fringe benefits, lost back pay, compensatory damages, and, in some cases, punitive damages.

Against this legal background, many people wonder whether they should inform their employers of their HIV status. The decision to tell your employer about your status is a very personal choice. If you decide to tell, however, you should make certain that the ADA covers your employer. You should also determine whether you should request reasonable accommodation. When you tell your employer, you should insist that the information be kept in the strictest confidence as the law requires.

# PEOPLE WITH HIV HAVE A RIGHT TO HEALTH CARE

## HEALTH INSURANCE

People living with HIV are justifiably concerned about continuing access to health care. In this country, most people gain access to health care through either individual or group health insurance policies. Some obtain health care through Medicaid or Medicare. This portion of this section concentrates on your rights to obtain health care through insurance policies.

First, if you do not presently have health insurance on your own or through a job, it may be very difficult to obtain. Under state and federal laws, insurance companies can decline to insure persons with illnesses, including HIV

If you decide to apply for health insurance coverage, you may be required to answer questions about your health on an insurance application. If you are not truthful about your health status, and if the insurance company discovers that you were untruthful within two years after you get the policy, the insurance company has the right to cancel your policy. If the company does not discover that you were untruthful during the first two years of your coverage, the company cannot cancel your policy and must pay your claims.

One other way that you may be able to get insurance is by going to work with an employer who offers insurance through "open enrollment." That means that you can qualify for insurance coverage just because you work there. It does not matter what your health status is. The insurance company must cover you in this situation, although it may be able to deny your HIV-related claims for a period of time through any "pre-existing condition" exclusion in the policy.

## WHAT IS COBRA?

Second, if you already have health insurance through a job and lose or leave your job, you may have the right to continue your group health insurance coverage. Under a federal law called "COBRA", you may be able to continue your group coverage for up to twenty-nine (29) months regardless of your health status.

You are eligible for COBRA continuation if you work for an employer with twenty (20) or more employees. COBRA is available to you if you quit due to disability, quit to get another job, if you are laid off, and even if you are fired, as long as you are not fired for "gross misconduct."

COBRA continuation begins as soon as your old coverage ends. The period that COBRA coverage lasts varies. Typically, you can keep COBRA coverage for 18 months. If, however, you were disabled within the meaning of Social Security law at the time you lost or quit your job, you can keep COBRA for 29 months (at which time you may be eligible for Medicare benefits under federal law).

Your employer or insurance company must notify you of your right to continue coverage under COBRA within forty-four (44) days of your losing or leaving your job. Once you receive this notice, you have sixty (60) days to decide whether you want to continue your coverage and make a "COBRA election." You then must pay your first premium within forty-five (45) days of making your COBRA election. You can be required to pay all back premiums for the sixty and forty-five day waiting periods all at once.

If you apply for Social Security disability benefits, and are found to be disabled at the time you left or lost your job, you must notify the insurance plan administrator within sixty (60) days of the date of the Social Security Administration's determination. This will entitle you to 29 months of COBRA coverage.

To keep your COBRA coverage, you must pay all premiums as they become due. The premiums may be no higher than 102% of the total cost of your group coverage. If you are eligible for COBRA coverage for 29 months because of disability, however, your premiums may go up after the eighteenth month. They may go up to 150% of the total cost of your insurance coverage. Benefits and coverage under COBRA continuation must be identical to those provided to current employees.

Even after your COBRA continuation expires, you may have the right to continue your health insurance coverage by converting your group policy to an individual policy. Conversion to an individual policy is also an option for persons who cannot get COBRA continuation because their employers do not have 20 or more employees.

You may be entitled to convert your policy under Georgia law if you have been continuously covered under the employer's group plan for a period of six months or more. You have a right to convert regardless of your health status.

If you convert to an individual policy, the premiums are likely to be higher than your group insurance premiums. Coverage may also be less comprehensive (this mean you may have less coverage, and more out of pocket expenses). Under Georgia law, insurance companies do not have to pay more than 80% of major medical costs under a converted plan.

The advantage of a converted plan is that you can maintain coverage as long as you pay the premiums. The insurance company cannot single you out for higher premiums, less coverage, or cancellation because you are sick. On the other hand, an insurance company does not have to let you convert if you are eligible for Medicare. Also, your coverage can be terminated if the insurance company stops offering individual conversion policies to everyone in the State.

## Other Health Insurance Options and Issues

Other than COBRA continuation and conversion, you may have other options to maintain your health insurance coverage. Extension of benefits for disabled persons, and Georgia's "little COBRA" may help you continue to receive coverage. You should consult with your benefits coordinator or an attorney about your options.

Other issues involving health insurance coverage include problems with "pre-existing condition" limitations, denial of payment for "experimental treatment", and bureaucratic delays in getting your claims paid. You should know that regardless of what the insurance company says, you have rights that may require the company to pay your claims in spite of these issues. Again, you should consult an attorney if you believe that the insurance company is not treating you fairly.

# HOW TO MAXIMIZE YOUR INCOME

Another critical issue for people living with HIV is the loss of income that happens when they stop work due to disability. While most persons in this situation will be eligible for Social Security disability benefits, these benefits are frequently not enough to help you pay your expenses. You should therefore be aware of options you have to maximize your income.

First, you may be eligible for benefits under disability insurance policies you own or have through your employer. These policies typically pay 60-70% of your salary to you if you become disabled. Be aware that there may be "pre-existing condition" limitations in your policy, or other issues that might cause the insurance company to deny your claim for benefits. If this happens to you, you should seek legal advice about how to obtain the benefits due you under these policies.

Second, you should know that you have the right to return to work and still receive your Social Security benefits under certain rules. Working while you are receiving Social Security is perfectly legal as long as you follow these rules. Please call the AIDS Legal Project (404) 614-3969, for specifics about these rules.

## SELLING YOUR LIFE INSURANCE

Finally, you may be able to receive substantial sums of money by "cashing in" your life insurance policy. Both group and individual term life insurance policies can be cashed in prior to maturity in exchange for a lump sum payment. Two methods are often available. The first is "viatical settlement" where you sell your policy to a "viatical settlement" company in exchange for a percentage of the death benefit under the policy. Depending on your health status, you can receive 50-80% of the death benefit in exchange for your policy. The second method is referred to as "living benefits" or "accelerated benefits". This involves a transaction between you and the insurance carrier whereby the carrier pays up to 90% of the death benefit to you while you are living, and reserves the remainder for your beneficiaries. You should review your policy to determine whether you have the "living needs" or "accelerated benefits" option.

You should be aware that cashing in your life insurance policy is a taxable event and could have an adverse effect on public benefits such as SSI and food stamps (It does not have an effect on SSDI benefits, however). While there are proposals pending to make "accelerated benefits" non-taxable, they have not been finalized. Furthermore, these proposals do not address "viatical settlements."

When dealing with "viatical settlement" companies, you should be a smart consumer. Bargain for the best price for your policy. Shop around and apply with more than one company. Be sure that the purchase money for your policy is placed in an escrow account by the company before you sign over your policy. If you have problems with a viatical settlement company, you should seek legal advice.

# PEOPLE WITH HIV HAVE A RIGHT TO APPROPRIATE HOUSING

If you are able to secure enough income, chances are you will not have problems maintaining your home or apartment. Sometimes, though, landlords or other housing providers have attempted to deny housing to people with HIV solely because of their status. This kind of discrimination is illegal.

Both the ADA and the federal Fair Housing Act prohibit discrimination in housing by landlords, lenders, zoning officials, nursing home operators, hospices, group homes and homeless shelters. Persons with HIV cannot be denied appropriate housing opportunities simply because they have HIV. If you feel that you have been discriminated against in housing, you should seek legal help immediately.

# PEOPLE WITH HIV HAVE THE RIGHT TO CONTROL THEIR FUTURES

One of the most striking and admirable characteristics of people living with HIV is the extent to which they insist on maintaining personal control over decisions related to their health care and business affairs. Maintaining this control is one of the keys to long-term survival. There are legal steps you can take to make sure that your decisions concerning your health care and business affairs are respected and followed.

## Durable Power Of Attorney For Health Care

With respect to decisions involving your medical treatment, one of the most important legal tools for people with HIV is the "Durable Power Of Attorney For Health Care." This legal document allows you to appoint someone you trust to make medical decisions for you if you cannot due to disability. You can also make sure that the person you appoint can visit you in the hospital and have access to your medical records. Health care personnel are required by law to follow the decisions made by your appointed agent. *(Operation: Survive! Committee Note: There is a copy of the Georgia Durable Power Of Attorney For Health Care form in Appendix A of this workbook. This is meant as a guide only. Once you've completed your Power of Attorney, you need to have a lawyer review it.)*

When you decide to execute a durable power of attorney for health care, it is critical that you select as your agent someone you trust implicitly. You can select a family member, friend, lover, or anyone else that you trust to be your agent. You should have a lengthy conversation with your agent concerning your philosophy of health care, your feelings about life support, and other issues that could come up during the course of your care. It is also advisable to select an agent who lives in close proximity to where you live so that the agent can stay in close touch with your health care providers. After you have executed a durable power of attorney for health care, you should provide copies to your health care providers so that they will know that they must consult your agent if you are unable to make decisions.

With respect to your business affairs, you should consider executing both a general power of attorney and a last will and testament. Under the general power of attorney, you can select an agent to carry on your business affairs, such as banking or insurance transactions, if you are unable to do so yourself due to illness. Under a last will and testament, you can determine how your property should be distributed if you should die.

Sometimes people are reluctant to execute these documents because they think they are too depressing or they think that signing a will means that they are giving up. But this is not the case. Executing these documents while you are in a well state is an important aspect of self-empowerment. If you do not have these documents already, you should consult with an attorney and complete them now.

# OBTAINING LEGAL ASSISTANCE

If you need legal assistance with any of the issues discussed in this section, you should contact a private attorney who is experienced and sensitive to your needs. If you meet income and other criteria, you may be eligible for assistance from the AIDS Legal Project, a unit of the Atlanta Legal Aid Society. The AIDS Legal Project can be reached at (404) 614-3969.

# FOOTNOTES

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# NOTES

# NUTRITION

# HIV NUTRITION : PRIMARY THERAPY [1]

## NUTRITION RELATED FACTS:

- **Malnutrition** is the second leading cause of death in persons with HIV/AIDS.
- **Wasting** of muscle is greater than total loss of body weight.
- **Timing of death** is related to degree of loss of lean body mass.
- **Poor Nutrition** alone weakens the immune system.

## IMPORTANCE OF NUTRITION

**Consequences of inadequate nutrition:**

1. Weight loss
2. Fatigue
3. Increased medication side effects
4. Higher rates of infection
5. Prolonged hospitalization
6. Decreased survival

**Nutrient deficiencies further weaken the immune system.**

1. Kaposi's sarcoma, PCP, Burkitt's lymphoma are associated with protein-calorie malnutrition.
2. Micro nutrient deficiencies weaken body processes, including the immune system.

## HIV / AIDS AND NUTRITION

**Decreased nutrient intake / availability**

1 Poor appetite  
2. Maldigestion and malabsorption  
3. Medication side effects  
4. G.I. symptoms: nausea, vomiting, diarrhea, sore mouth, taste changes

**Accelerated use of vitamins and minerals even in early a symptomatic stages.**

1. Vitamins A, C, E, B6, Bl2
2. Selenium, zinc, copper

**Increased protein utilization.**

1. Antibodies, immune cells
2. White and red blood cells
3. Tissue binding and repair

**Wasting of lean body mass greater than decrease in total weight loss.**

1. Decrease cardiac function
2. Decrease respiratory function
3. Death is related to magnitude of tissue depletion; independent of underlying cause of wasting
    a. loss of 50% premorbid weight  
    b. loss of 30% ideal body weight

# NUTRITION SUPPORT IN AIDS $_2$

### INTRODUCTION

Significant weight loss and malnutrition are problems that frequently accompany HIV infection and AIDS. As with any chronic disease, severe malnutrition could decrease longevity, increase morbidity, and compromise the quality of life in persons with HIV/AIDS. Therefore, optimal nutritional status should be a goal of therapy at each stage of the disease, beginning with asymptomatic people who are HIV positive.

**The Task Force on Nutrition Support in AIDS set these goals for good nutrition:**

- Preserve lean body mass.
- Provide adequate levels of all nutrients.
- Minimize symptoms of malnutrition.

**The Task Force also offered these general nutrition recommendations:**

- Attain and/or maintain adequate caloric consumption. (An involuntary weight loss of 10% or more of usual body weight can be a sign of malnutrition.)
- Aim for optimal quality and quantity of protein during stressed states.
- A daily multivitamin/mineral supplement which supplies 100% of the Recommended Dietary Allowances (RDA) for each nutrient should be taken by those consuming an inadequate oral diet.

# NUTRITION [3]

The most important part of your treatment strategy for staying healthy or living longer remains things you can do for yourself. Nutrition is important for any body's good health, but HIV disease puts even greater demands upon our nutritional requirements. We need to stop thinking of nutrition as an "alternative" therapy and give it the attention it deserves. It must be an ongoing effort for long term health. Some important nutritional facts about HIV infection include:

- HIV infects intestinal epithelial cells, leading to malabsorption of nutrients especially B12, fat soluble vitamins and trace minerals, all of which are vital for normal immune function.
- HIV infection itself places additional metabolic, and thus nutritional, demands upon the immune system and lean body mass.
- HIV infection may eventually trigger wasting, brought on by endogenous cytokine hormones like interleukins. This greatly alters uptake and use of nutrients in an negative manner.
- Opportunistic infections lead to malabsorption (the body's inability to use the nutrients you eat), the inability to eat and places additional metabolic demands on your body.
- People with HIV infection show a variety of nutrient intake deficiencies, including deficient functional status of micro nutrients. This suggests a strong need for nutritional education and a change in previous dietary habits.

Nutrition is basic yet so vital to our survival. We get all wrapped up in the new glamour drugs and we forget how important it is to support our weakened immune system with good food. Nutrition has a strong bearing on effective treatments and helps to avoid complications that could further damage our health. In the absence of one or more nutrients the skin and the linings of the gastrointestinal and respiratory tracts atrophy and the barrier system is lost. In addition, the skin and other linings lose their ability to secrete mucous and acidic substances that kill bacteria; the mouth, stomach and upper intestines lose their ability to secrete enzymes that kill invading microbes. Given the importance of nutrition, it is amazing how cheap and easy a good nutrition program can be. And it does not have to be funny looking or awful tasting. Don't wait to start a good dietary program; nutrition is a long term project, not a quick fix. Remember healthy eating should be the rule not the exception. Let's now explore the basics of nutrition and HIV- high calories, high protein and low fat intake.

# PROTEINS

Long term protein deficiency is known to be a cause of immune dysfunction. Protein is necessary in the formation/sustaining of muscle tissue. It is also critical in energy conversion. When we are ill and not eating, we break down our own tissue for energy. Recent research has shown that when our body is under stress such as illness, fever, or infection it tends to rely more on muscle tissue than fat as an energy source.

Good sources of protein include: eggs, poultry (preferably free range and organically fed; corn fed should be avoided because of Omega 6-fats and fungal infestations of corn), deep water cold ocean fish (especially from the less polluted waters of Greenland and Iceland), grains, nuts, seed, dairy, soy products such as tofu and tempeh, and most meats that do not contain hormones, dyes or chemicals (especially sodium nitrate).

Protein should comprise at least 20% of your diet. On a 2800 calorie diet you need at least 140 grams of protein or 560 calories. Many nutritional supplements provide an easy way to consume needed protein. But, just increasing protein intake isn't enough. Large intakes of protein without exercise to build muscle stores can increase fatigue and make you sluggish. Protein requires a lot of energy to digest. Paradoxically, you'll gain energy if you expend it. When you're fit , your muscles are stronger, and your heart and lungs deliver oxygen more effectively, putting more power at your disposal and making routine tasks less tiring.

A different kind of protein supplementation is exercise. Regular exercise is highly beneficial. Also, if you want or need to gain weight, you need to do so through exercise. Padding yourself with fat is not particularly helpful. If an opportunistic infection occurs, you need protein stores to resist it and make the drug therapies your doctor prescribes work effectively.

Immunity is based on protein stores and exercise promotes protein formation in tissues throughout the body. Here, resistance exercises such as weight lifting, are more important than aerobic exercise if done in moderation (8 to 12 repetitions). Aerobic exercise burns proteins. However, when you perform aerobic exercise, the body's increased oxygen demand forces the bone marrow to produce more blood which is great for fighting anemia.

When exercising, caution should be taken not to bring the heart rate above 75 percent of it's maximum capacity. Any exercise program should be designed with the individual's capacity rather than external, inappropriate goal. Again, using moderation is the important thing.

Also anaerobic exercise should be eliminated or sharply reduced. Examples of anaerobic exercise are sports such as tennis, basketball and racquetball. Anaerobic exercise produces harmful physical stress that lowers the immune system.

Another strategy that promotes protein building is regular, frequent meals. People that have four meals a day have better nitrogen balance than those that eat three or less. If you feel the protein in your diet is adequate but you are unable to increase your protein stores, check with your doctor. Testosterone is needed to convert protein to muscle. Testosterone shots are available to correct any low levels you might have.

You can check your protein levels by having the albumin in your blood tested; it is a good indicator of the body's protein stores.

# FAT

Fats provide a source of the essential fatty acids that the body needs for metabolism, cell maintenance and the production of specific fats. They also transport certain fat soluble vitamins into the body and through the walls of the digestive tract. Fats also contribute to that "full" feeling. Fats provide a concentrated source of calories; 9 calories per gram, as compared to proteins and carbohydrates which have 4 calories per gram. Inadequate fats may result in dermatitis or an essential fatty acid deficiency.

Dietary fats dilute the nutritional value of food by increasing the calories without increasing nutrient value. Fat is emptied from the stomach and digested more slowly than other nutrients, this may contribute to feelings of nausea and anorexia. During "futile cycling" fat stores are changed into a usable energy form then changed BACK into a storage form. Obviously this means that fat is never put to use as an energy source. As HIV infects intestinal epithelial cells, it is very important to reduce the amount of fat that can clog the remaining healthy cells. Problems with fat utilization or fat malabsorption may also result from an infection in the pancreas (the organ that makes and secretes an enzyme called lipase, which breaks down fat) or in the liver ( the organ that makes bile, which packages fat into a form your body can absorb). High fat diets almost always result in severe bouts of diarrhea.

Some trace minerals such as zinc and copper may bind or join with unabsorbed fatty acids to form a "soap." This "soap" causes minerals to pass through the GI tract unabsorbed, which contributes to diarrhea. A high (soluble) fiber diet is a good way to control diarrhea. Once in the body , fiber tends to attract and bind with fat. Because fiber is indigestible, it's quickly excreted, speeding any fat nearby through the system before it can be absorbed into the blood and stored as flab. Most high-carbohydrate foods are naturally loaded with fiber , but any kind of processing depletes them of it. Good examples of soluble fiber would include foods such as oatmeal, rice, beans and pastas.

In searching for agents that block abnormal metabolism, scientists are studying the use of Omega-3 fatty acids. These are a type of fatty acid found in high quantities in fish oil which have anti-inflammatory effects in animal experiments. It should be noted that benefits from Omega-3 are only seen if a reduction in Omega-6 is made at the same time. Asymptomatic HIV+ persons seemed to benefit from this more than those at end stage AIDS; however, more studies are needed. In general, use cold pressed oils. If you must, use natural sweet butter; avoid hydrogenated or partially hydrogenated oils and fats. When we speak of fats we are usually speaking of triglycerides. Most fat in our diet is made up of long chain triglycerides. MCT oil is a medium chain triglyceride which is easy for your body to digest and absorb and doesn't contribute to persistent diarrhea. MCT oil, even though expensive, is available by prescription.

Fats should not comprise more than 20% of your diet. On a 2800 calorie diet no more than 63 grams or 560 calories of fat should consumed. Remember that each gram of fat equals 9 calories. Foods low in fat include: low fat yogurt, cottage cheese, 1% milk or buttermilk, cereals with the exception of granola, broth soups, vegetables, fruits, juices, angel food cake, pretzels, soda crackers, sherbet, spaghetti with plain sauces, crab, white fish, shrimp, light tuna in water, legumes, veal, turkey breast and lean cuts of beef or pork braised or roasted without fat.

The easiest way to reduce fat is to eliminate high fat foods. However, a great deal of fat savings can be accomplished by simply reading the labels of the food you buy, as the chart on the next page illustrates.

# EASY WAYS TO CUT FAT

| Switch from | To | Save |
|---|---|---|
| 2 tb fudge topping | 2 tb chocolate syrup | 4 gm |
| 1 slice french toast | 4" pancake | 5 gm |
| Snickers bar | 3 Musketeers bar | 5 gm |
| 3 oz chicken w/ skin | 3 oz skinless chicken breast | 4 gm |
| 1 large egg | 1/4 cup Egg Beaters | 5 gm |
| 1 slice bologna | 1 slice 95% fat free ham | 3 gm |
| 3 oz breaded shrimp | 3 oz boiled shrimp | 9 gm |
| Ramen noodles, pork | Chicken noodle soup | 6 gm |

# WAYS TO ADD CALORIES

### FAT

Fat is the best source of calories. Fat is often unwanted in a "healthy diet." When unplanned weight loss occurs, fat is important in regaining weight. Fat makes every bite you eat count! If you can tolerate fats add them to your food at each meal.

Sources of fat: butter, margarine, oils, salad dressing, mayonnaise, gravies, cream cheese, peanut butter, half and half cream, olives, avocados, and ice cream.

### SUGAR

Sugar is also a good source of calories. Like fat it is good for weight gain. Add sugar to cereals, coffee, and tea. Add jams, jellies, honey, and syrups to breads. Eat fruits canned in heavy syrup or dried fruits.

Sources of sugar: Table sugar, honey, syrup, brown sugar, jelly, jam, molasses, desserts (cookies, cakes, pies, doughnuts, pastries), and candy.

# WAYS TO ADD PROTEIN

Protein is very important in forming cells, building muscles, repairing tissues and maintaining a strong immune response especially with HIV infection. Proper protein use depends on adequate calorie intake so a balanced diet is important. Without adequate calorie intake protein is used to supply energy. Inadequate intake of calories and protein causes the body to use the body's protein (muscle) for fuel.

- Eat foods high in protein: beef, chicken, pork, fish, milk, yogurt, cheese, eggs, rice and beans, nuts, and peanut butter.
- Add dry powdered milk to foods.
- Use "Double Strength Milk" in food preparation. Mix one cup dry powder milk with four cups whole milk. Allow to chill in the refrigerator before drinking.

# NUTRITIONAL GUIDELINES

- ✔ Eat nutrition dense foods.
- ✔ Eat live foods (not pasteurized) in fruit, vegetables and nuts these contain enzymes that help your body digest them.
- ✔ Use cold pressed oils.
- ✔ Use natural sugars when possible (honey or fruit). Yeast loves sugar, bread, dried fruits and alcohol. Counter with vinegar.
- ✔ If taking antibiotics and steroids (they kill friendly bacteria and give you diarrhea), eat yogurt to help restore balance. Make sure the yogurt you buy has live cultures (acidophilus).
- ✔ Garlic is considered a natural antiviral.
- ✔ Eat protein first with undiluted acid in the stomach to speed digestion; follow with starches.
- ✔ Drink a lot of DISTILLED water; 64-80oz daily.
- ✔ Eat fruit by itself on an empty stomach as dessert or a snack.
- ✔ Eat peacefully and slowly and chew all food well.
- ✔ Eating carbohydrates before bedtime enhances sleeping.
- ✘ Avoid preservatives and additives (especially Sodium Nitrate).
- ✘ Avoid hydrogenated and partially hydrogenated oils and fats.
- ✘ Eating protein late at night can contribute to insomnia.

**RESOURCES**

- American Dietetic Association 1(800) 366-1655 to speak with a registered dietician.
- Georgia Dietetic Association, 2850 Faraday Court, Decatur, GA (404) 634-1728
- Grady Infectious Disease Program Nutrition Department.
  Shelly Moorwessel, MMSc, RD, LD. (404) 616-9797

# APPETIZING IDEAS TO IMPROVE FOOD INTAKE 4

If you are experiencing a loss or change in appetite with a relative decrease in food intake that is leading to weight loss, try some of the following tips:

- Eat small, frequent "snacks" throughout the day, perhaps 300 calories each, taken every 2 hours or so.
- Concentrate on nutrient-dense foods and drinks and avoid filling up on low or no calorie foods.
- Prepare meals ahead of time which can be divided into individual servings and frozen until ready for use.
- Keep easy-to-prepare foods on hand, such as frozen dinners, canned foods and eggs.
- Have your favorite foods in a pleasant atmosphere and encourage the presence of family members or companions during meals.

## LOADING UP ON CALORIES & PROTEIN

To maintain weight or encourage weight gain, it is important to consume calorie-laden proteins, carbohydrates, and fats. Alcohol also provides calories, but should not be used as a calorie source because it has been shown to depress the immune system. Fat contains more than twice the number of calories by weight than protein and carbohydrate. Increasing fat in your diet may be an easy way to boost your calorie intake. Sources of fats include saturated fats (butter, cream, ice cream, whole milk, cheese, cream cheese, sour cream, high-fat meats); monounsaturated fats (olives, avocados, peanut oil), and polyunsaturated fats (corn and sunflower oils).

**To Increase Calories & Protein:**

- Use whole milk, cream, half & half or a high-calorie non-dairy creamer in cooking and on cereals.
- Add generous amounts of lowfat margarine, cream cheese, sour cream, cheese, and mayonnaise to bread, pasta, rice, potatoes, vegetables, and other foods.
- Add whipped cream or frosting to desserts.
- Add sauce or gravy to meat, fish, chicken, vegetables, potatoes, rice, noodles, and other foods.
- Add non-fat dry milk to foods for added calories and protein.
- Use dried fruit, nuts, granola and/or brown sugar on cereals, ice cream or other desserts.

# ACTIONS TO PREVENT WASTING

## ADEQUATE INTAKE DURING OPPORTUNISTIC INFECTIONS

1. Symptom management
2. Appetite stimulants
   - marinol
   - megace
3. Nutrient priorities

**Fluids**

You need to drink plenty of distilled water, this is even more important if you are taking medications.

- 16 - 17 ml per pound of body weight or 1 cup for each 15 pounds of body weight
- Add 500 ml for each degree temperature> 37°C

**Calories**

asymptomatic: 14 - 16 kcal / lb / day
symptomatic: 16 - 20 kcal / lb / day
12% increase for each degree temperature> 37°C

**Protein**

a symptomatic: 0.5 - 0.7 gm /lb / day
symptomatic: 0.5 - 1.1 gm / lb day

**Micronutrients**

Multivitamin - mineral supplement

## EXERCISE

1. Three sessions per week
2. Resistance training - 1 set to fatigue
   Resistance rubber band or towel: Hold exercise position for seconds and slowly release. Rest for 10 to 15 seconds and repeat for a total of 10 repetitions
   Hand Weights: Adjust weight to produce fatigue at 6 - 10 repetitions. Increase weight if > 20 reps required to produce fatigue.
3. Aerobics - do only mild, low impact.

## DIARRHEA

Diarrhea is often the first gastrointestinal symptom resulting from infections, medications, or changes in the intestinal lining. The type and degree of diarrhea may vary according to the cause and individual tolerance. Diarrhea can lead to the loss of fluids and electrolytes (minerals such as potassium and sodium), causing dehydration and electrolyte imbalances.

**If Diarrhea is a Problem:**

- Try small frequent meals served at room temperature.
- Replace fluids and electrolytes with liquids such as water, broth, fruit juices, jello, popsicles, and Gatorade; eat high potassium foods, such as bananas, apricot and peach nectars, meat and potatoes.
- If milk causes diarrhea, use Lactaid to break down the lactose before drinking milk; try yogurt and cheeses in small amounts.
- If fats seem to cause diarrhea, use the leaner counterparts of the foods you prefer, such as low-fat cottage cheese, part skim milk cheeses, and leaner cuts of meat.
- If cramping is a problem, avoid foods that may cause gas or cramps, such as carbonated drinks, beans, cabbage, broccoli, cauliflower, highly spiced foods, too many sweets, and sorbitol sweetened chewing gum.
- Avoid caffeine-containing foods and beverages, such as coffee, chocolate, and some carbonated beverages.
- Oatmeal, apples, pears, potatoes and other foods from the fruit/vegetable and cereal/grain groups are good sources of certain types of fiber (pectins and gums) that may help to alleviate diarrhea. Limit bran types of fiber, seeds, and husks on grains.

## NAUSEA

Nausea may be caused by infections as well as some medications and treatments.

**If Nausea is a Problem:**

- Eat easily digested foods, such as rice, soft cooked or poached eggs, and custard.
- Avoid greasy, high fat, and spicy foods.
- Eat saltier foods and avoid overly sweet foods.
- Drink fluids through a straw; drink fluids between instead of with meals.
- Eat small, frequent meals to avoid an empty stomach.
- Avoid foods with strong aromas.
- Try cold entrees, such as meat, tuna, or egg salad sandwiches and cottage cheese with fruit.
- Eat drier foods, such as toast or crackers.
- If vomiting, replace fluids and salt by consuming ginger ale and juices.
- Do not lie down immediately after eating.
- Eat more food when you feel better and avoid favorite foods during times of nausea to keep from being “turned off”.

## FATIGUE

People with HIV and AIDS often experience fatigue, making it difficult to spend the time necessary to prepare meals and maintain adequate food intake.

**If Fatigue is a Problem:**

- Prepare meals ahead of time when you feel well and freeze in individual servings.
- Keep easy-to-prepare foods on hand, such as frozen dinners, canned foods, eggs, tuna, and noodles.
- Eat small frequent meals.
- Accept offers of family and friends to help prepare meals.
- Try take-out food restaurants.
- If you have AIDS, call Project Open Hand (404) 525-4620 to take advantage of in-home meal delivery.

## ORAL/ESOPHAGEAL CAVITY DISORDERS

Oral and esophageal complications are common in people with HIV and AIDS and may interfere with the ability to eat. Changes in taste perception may also occur.

## DIETARY CHANGES THAT MAY HELP:

### Mouth Sores/Pain

- Avoid citrus and pineapple.
- Avoid extremes in food temperature.
- Choose non-abrasive, easy to swallow foods.
- Spices & salt may not be tolerated.
- Avoid acidic foods/beverages if there are open lesions.
- Adjust textures to soft or liquid as tolerated.
- Avoid "hot" spices if open lesions.

### Dulled Taste Sensation

- Provide acids to breakdown mucus.
- Provide extremes in food temperature to stimulate appetite.
- Eat a variety of textures.
- Use seasonings as tolerated to stimulate appetite.

### Swallowing Dysfunction

- Choose extremes (Hot or Cold) to stimulate sensation.
- Foods of semi-solid consistency (oat meal, mashed potatoes) are ideal.
- Use seasonings to stimulate mouth sensation.

# NUTRITIONAL SUPPLEMENTS

There are two types of nutritional supplements. Some provide calories (energy nutrients) from proteins, carbohydrates, and fats as well as the non-energy nutrients in vitamins and minerals. Others provide only vitamins and minerals.

## COMMERCIAL CALORIE-CONTAINING SUPPLEMENTS:

If you are unable to eat adequate foods, you may want to get a commercial supplement that includes calories as well as vitamins and minerals. Products are available in either powdered or ready-to-use forms that can be taken "as is" or mixed into milk, water, or added to recipes. The following products are available in grocery stores and/or pharmacies:

- Advera (specifically for people with HIV)
- Ensure (lactose-free)
- Ensure Plus (lactose-free)
- Resource Crystals (lactose-free)
- Carnation Instant Breakfast
- Nutriment
- Enrich (lactose-free, soy fiber)
- Osmolite (lactose-free, no sugar)
- Meritene Powder
- Sustacal
- Vivonex TEN

## Vitamin and Mineral Supplements

The Task Force on Nutrition Support in AIDS recommends that individuals with HIV or AIDS consuming an inadequate diet should take a daily multivitamin/mineral supplement which supplies 100% of the Recommended Dietary Allowances (RDA) for each nutrient.

# NUTRITION SUPPORT OPTIONS

When the dietary needs of any medically compromised person cannot be met by a regular, well-balanced diet, a physician may prescribe alternative nutrition support. This may either involve tube feeding into the gastrointestinal tract or intravenous feeding, when the G.I. tract is not functioning properly.

**Enteral Tube Feeding:**

Liquid formula containing complete, balanced nutrition is fed through a tube into the gastrointestinal tract. There are several different types of tubes used and several sites for tube feeding. The tubes are named for the site of entry into the body and the location of the tip of the tube. For example, a nasogastric tube enters by way of the nose (naso-) and goes down into the stomach (-gastric). If the tube enters through a surgical opening, the word will end in "ostomy". A gastrostomy tube enters the stomach through a surgical opening in the abdomen.

**Parenteral (Intravenous) Nutrition:**

Parenteral nutrition may be used when feeding into the G.I. tract is not feasible, perhaps due to maldigestion or malabsorption. In this case nutrients are fed directly into the venous system, generally through a central catheter which is surgically placed in the chest area. During the last stages of the disease, the family or friends, primary caregiver, and the patient's prior wishes should be included in the decision on whether to feed parenterally.

# A BALANCED MENU PLAN

- Drink two cups of milk, or more, per day. Cheese, cottage cheese, buttermilk, yogurt, and ice cream may be substituted.
- Eat two or more 2- or 3-ounce servings of meat or a meat substitute daily. Meat substitutes include eggs, fish, poultry, dried beans and peas, peanut butter, and nuts.
- Eat or drink two or more half-cup servings of fruit or fruit juice daily. One should be a citrus fruit or juice. Fruits or juices can be fresh, frozen, or canned. Eat what you like best.
- Eat two or more half-cup servings of vegetables daily. One should be a dark-green leafy vegetable or a yellow vegetable.
- Eat four or more servings of bread or cereal. Eat other foods such as desserts, margarine, soups, and beverages as desired.
- Include nutritious snacks such as nuts, cheese, and crackers between meals and before bedtime.

# SAMPLE HIGH-CALORIE MEAL PATTERN

**Breakfast:**
- Chilled Apricot Halves
- Avocado-Tomato-Bacon Scrambled Eggs
- Buttermilk Biscuits w/ Margarine & Honey
- Fortified Whole Milk (2 tb. non-fat dry milk added)

**Mid-morning Snack**:
- Banana Nut Bread w/ Cream Cheese
- Large Apple Juice

**Lunch**:
- Cheeseburger
- Oatmeal-Raisin Cookies
- Fortified Whole Milk

**Mid-afternoon Snack:**
- Pound Cake topped w/ Sweetened Strawberries & Whipped Cream
- Cafe au Lait

**Dinner:**
- Cream of Broccoli Soup
- Pork Medallions w/ Tarragon Mustard Sauce
- Rice Pilaf
- Spinach Souffle
- Croissants w/ Margarine
- Orange Julep (Orange Juice, Club Soda, Mint)

**Evening Snack**:
- Peanut Butter/Crackers
- Fortified Milk

## SNACK IDEAS GO 'ROUND THE CLOCK

**Salty Foods**:
- Mug of Soup (Cream-style or bean)
- Crackers
- Finger Sandwiches (Crust removed)
- Mini meat pies
- Mini pizzas
- Pate/ French Bread
- Peanut Butter & Crackers
- Cheese & Crackers
- Dried fruit & nuts
- Guacamole
- Tortilla chips

**Sweet Foods**:
- Quick Breads—Gingerbread, Banana Nut Bread, Pumpkin Bread, Zucchini Bread, etc.
- Oatmeal-raisin cookies
- Fig Newtons
- Puddings, Custards, Mousses, Souffles
- Frozen or fruited yogurt
- Ice Cream
- Graham Crackers

# HIGH CALORIE / HIGH PROTEIN DIET FOR PEOPLE WITH HIV [5]

**Basics**

✔ **Eat at least three meals and three snacks every day.**
Keep the meals small and simple at first. Slowly add more food at meals.

✔ **Keep easy to fix snack foods on hand and within reach.**
Make everything you eat count ! Choose from the following list of snack foods:

Cheese and crackers
Townhouse Crackers
Ritz Crackers
Triscuits
Granola
Dried Fruit
Ice cream / sherbet / frozen yogurt
Custard
Cottage cheese and fruit
Popcorn with margarine
Cookies: oatmeal, molasses, peanut butter
Muffins: banana nut, blueberry, bran
Hard-boiled eggs
Liquid supplements: Sustacal, Ensure, lipisorb
Peanut butter and crackers
Milk Chocolate
Milk
Milkshakes / Malts
Trail mix
Nuts
Pudding
Yogurt with fruit
Fruit canned in heavy syrup
Peanut butter and jelly sandwich
Poptart / Toasters
Potato chips and dip
Deviled eggs
Leftovers
Instant Breakfast mix

✔ **Fluids are important** but they can fill you up quickly, making it difficult for you to eat your meal. **Drink liquids after or between meals** not before or during meals. Coffee, tea, sugar free drinks, and broths have little calories or other nutrients so try to avoid them. If you drink coffee or tea be sure to add extra sugar and milk or cream for calories. Drink liquids that have calories and other nutrients such as milk, milk shakes, cream soups, Koolade, lemonade, fruit juices, fruit punches, and liquid supplements

✔ Eat your meals in a **relaxing and pleasant atmosphere** when possible.

✔ **Eat well on your "good days"** to make up for the "bad days "

✔ **Eat a well-balanced diet** including a variety of foods from the five food groups. Use the Food Guide Pyramid to help with your choices.

# FIVE-A-DAY FRUIT AND VEGETABLE GUIDELINES [6]

The U.S. Department of Health and Human Services, the Department of Agriculture and the National Academy of Sciences all recommend we eat a balanced diet low in fat with plenty of fruits and vegetables—valuable sources of vitamins. In fact, the National Cancer Institute has begun a "5-a-Day" program to increase consumption of fruits and vegetables to a total of five servings daily by the year 2000. Their suggestions for meeting this goal:

### MORNING

- Drink a glass of juice.
- Add sliced bananas or strawberries to cereal.
- Have a bowl of fruit such as melon or peaches.
- Top pancakes with fruit instead of syrup.

### LUNCH

- Have a salad or soup that contains vegetables.
- Add zucchini, carrot or celery sticks to a brown bag lunch.
- Eat a piece of fruit such as an apple or orange, plum or kiwi.
- Add lettuce, sprouts and tomatoes to your sandwich.

### SNACK

- Nibble on some grapes.
- Take along dried fruit such as raisins, apricots, prunes or figs.
- Choose a glass of juice.
- Keep cut raw vegetables in water in the refrigerator.

### DINNER

- Add vegetables to the main dish, such as broccoli to pasta or a casserole.
- Add raw vegetables or fruit to a green salad.
- Use fruits as a garnish on main dishes.
- Order extra vegetables when eating out.

### DESSERT

- Liven up a plain dessert with fresh fruit.
- Top frozen yogurt with pineapple or papaya.
- Add chopped fruit or berries to muffins, cakes or cookies.

# OTHER HELPFUL HINTS

## LOSS OF APPETITE

- Eat well during your "up" times.
- Make your mealtimes as relaxed and pleasurable as possible.
- Include a relaxing walk before mealtime. Fresh air often helps.
- Use ready-to-eat, easily prepared food, freezing meals ahead of time whenever possible.
- Take advantage of time-saving appliances, like blenders and microwaves.
- Keep a variety of nutritious snack foods on hand, such as cheese and crackers, muffins, nuts, puddings, and nutritional supplements.
- Be flexible. If you aren't hungry at dinner time make breakfast, mid-morning snack, and lunch your main meals.
- Try a variety of new tastes and textures to find those that appeal to you most.
- Try to get plenty of sleep every night.
- Chew slowly, and take breaks during mealtime.
- Maintaining your weight is important. Make an effort to eat regularly, even if it's only a few bites.
- If you are losing weight, high-calorie liquids such as milk shakes and nutritional supplements like Sustacal or Advera may be recommended.

## TASTE PROBLEMS

- If red meat tastes unusual, substitute chicken, dairy products, ham, eggs, and fish for your protein needs.
- Try cold foods like cheese, milkshakes, cold cuts, tuna fish, or egg salad.
- Adding sugar can mask the flavor of salty foods.
- Adding salt can decrease the sweetness of sugary foods.
- Try stronger seasonings, such as those used in Italian, Mexican, and curried dishes.
- Marinate food in wine, fruit juice, beer, soy sauce, butter, or barbecue sauce.
- If food tastes metallic, use plastic utensils and dishes whenever possible.
- Try sugar-free candies or gum to eliminate bad taste. Fresh fruits also leave a pleasant taste in the mouth.
- Drink your nutritional supplement cold, through a straw, if it smells bad to you.
- Tart foods may overcome a metallic taste. Try citrus juices, cranberry juice, pickles, or relish.
- Freshen your mouth by using a mixture of 1 teaspoon of baking soda to 2 cups of warm water.
- Check with your doctor if the condition persists.

## MOUTH PROBLEMS

### Dry Mouth

- Sip on juices and other fluids throughout the day.
- Use extra butter, gravies, sauces, salad dressings, yogurt, and mayonnaise to moisten foods.
- Dunk or soak dry foods into liquids.
- Sugar-free candies and gum, or ice chips can be helpful.
- A room humidifier helps alleviate dry lips and mouth.

### Sore Mouth

- Try blended, smooth, and creamy foods such as eggs, soup, casserole, cheesecake, ice cream, and pudding.
- Avoid hot foods. Cold or room temperature foods are generally less irritating.
- Avoid acidic, spicy, rough, and salty foods.
- After meals, rinse with mild mouthwash (1 teaspoon baking soda to 2 cups warm water) to freshen your mouth. Avoid commercial mouth wash.

### Sore Throat and Swallowing Difficulty

- Choose soft-textured foods and use a food grinder or blender when necessary.
- Avoid hot or cold extremes. Room temperature foods may be soothing.
- Liquid nutritional supplements like SUSTACAL can help meet your nutritional needs.
- Use straws for drinks, and a cup or glass instead of a bowl and spoon for soups. Tilt your head backward or forward to make swallowing easier.
- Check with your doctor if the condition persists.

## ELIMINATION PROBLEMS

### Constipation

- For meals and snacks, eat high-fiber foods like whole grain cereals, breads and crackers, plus fruits and vegetables, dried beans, peas, and even popcorn.
- Drink plenty of liquids, especially in combination with high-fiber foods. Tea, hot lemon water and juices such as prune juice are effective.
- Take a walk or exercise as part of your daily routine.
- Add small amounts of bran whenever you cook or bake.
- Check with your doctor about medications to relieve constipation.

### Diarrhea

- Eat small meals throughout the day.
- Drink 8-10 large glasses of liquid a day to replace lost fluids, preferably between meals.
- Try non-irritating foods such as chicken, fish, eggs, white bread, canned vegetables, bananas, applesauce and smooth peanut butter.
- Avoid fatty and fried foods, rich sauces, caffeine, alcohol, cigarettes, and chocolate.
- Keep activity to a minimum after meals.
- Be careful with very hot or cold foods. Try to drink your liquids slowly at room temperature.
- If you have problems with gas and cramps, chew slowly with your mouth closed to eliminate swallowing air. Avoid carbonated drinks, spicy foods, beans, onions, and cabbage.
- Check with your doctor if the condition persists.

# CORE LIST OF NUTRIENTS FOR PEOPLE LIVING WITH HIV

The following list includes the nutrients that should probably be taken daily by virtually all those living with HIV infection, regardless of disease stage. The list is based on the nutrients that have most often been found to be deficient, even in early stages when CD-4 counts are still high. It is believed that deficiencies of these nutrients may create significant immune dysfunction, contributing greatly to the overall immune system decline. More than five dozen studies presented at the 7th (Florence, July, 1991), 8th (Amsterdam, July, 1992), and 9th (Berlin, July, 1993) International Conferences on AIDS emphasized the importance of nutrients for people living with HIV. A number of those studies reported that many deficiencies begin when CD-4 counts are still high and result in significant immune dysfunction. According to Marianna Baum, PhD, and her colleagues at the University of Miami Medical School, "multiple nutritional abnormalities occur relatively early in the course of HIV infection and appear to facilitate disease progression." These researchers also reported that to reach adequate blood levels of nutrients required consumption of 6 to 25 times (!!!) the RDA of the nutrients most often found deficient (B2, B6, B12, A, C, E, and zinc), and even at those levels some people still fell short! This obviously makes the recommendations made by some dietitians and physicians for only consuming RDA levels utterly, hopelessly, dangerously inadequate. Dr. Baum and her colleagues also clearly showed that at those dosage levels there was absolutely no evidence of any toxicity, a clear contradiction to the absurd warnings of toxicity so often issued by those same badly under-informed dietitians.

Following the core list (beginning on the next page) is a listing, by symptom, of the nutrient deficiencies that may be at least a partial cause of certain symptoms commonly seen in those living with HIV. Replenishment of these nutrients can often eliminate symptoms. Two cautions are in order. First, it is critical to remember that many of these symptoms can also be caused by infections or drug side effects. All symptoms should be discussed with a physician and careful consideration given to other causes; only when they have been ruled out should you consider particular nutrient deficiencies as a possible cause of a given symptom. Second, please remember that any supplementation aimed at specific symptoms must be in the context of a complete nutritional approach that provides resupply of all missing nutrients for best effect. Nutrients seldom work singly in the body. Rather they work as a package that only in whole effects total body changes such as immunological improvement and symptom elimination.

**Multiple vitamin/mineral:**

a bioavailable, hypoallergenic multiple using advanced forms of minerals (citrates, picolinates, ascorbates, etc.) and B vitamins (e.g., B6 in the form of pyridoxal phosphate rather than pyridoxine) is a must for best absorption/metabolism; take with 3 meals/day.

**Antioxidant formula:**

one with multiple antioxidants such as beta carotene, selenium, tocopherol, glutathione, etc.; one with each meal; HIV infection yields high levels of free radicals and oxidative damage which antioxidants counter; critical to address autoimmune component of HIV infection (therapeutic range for selenium is 400-800 mcg/ day; more than 1000 mcg total from all sources can be toxic; also will be found in most multiples; check totals).

**Acidophilus:**

1/4-1/2 teaspoon or 2-4 capsules before each meal. Naturally occurring intestinal microorganisms aid digestion & produce vitamins for the body. They are often deficient in HIV + s, particularly those on antibiotics or prophylactics, or those with candida problems. Supplements containing acidophilus and other probiotics can help to prevent candida overgrowth, digestive tract damage and malfunction, and diarrhea. The good bacteria directly attack yeast and produce chemicals such as lactic acid which suppress its growth; may also help to prevent infections like MAC or cryptosporidiosis or CMV from taking hold in the intestines, both by competing for space with the pathogens in a way that keeps them from colonizing the intestines and also by producing natural antibiotics and anti-parasiticals.

**Ascorbic acid/ascorbate:**

6-20 g (6000-20,000 mg)/day with meals; very important as antioxidant, antiviral, antibacterial, antifungal, anti-inflammatory (generally non-toxic; amounts beyond tissue saturation level can cause diarrhea; can cause urinary oxalate stone formation in those susceptible to forming such stones (a very small percentage of people); no other toxicities known, although myths, disproven or unfounded, abound).

**Beta carotene:**

50,000-200,000 IU/day; powerful antioxidant; critical to thymus; Yale University research has shown CD-4 increases at 100,000 IU/day (non-toxic even in large amounts; vitamin A, however, possibly toxic at more than 25,000 IU/ day, long-term).

**B-12:**

1000 mcg in form of nasal gel, 2-7 times per week; critical to prevent/eliminate fatigue and some forms of cognitive dysfunction/dementia/tinnitus/neuropathy.

**Coenzyme $Q_{10}$:**

30-300 mg/day; critical for immune function/heart muscle/periodontal health; levels decline as HIV progresses; may help prevent progression.

**Vitamin E:**

800-1600 IU/day; critical antioxidant; important if on AZT to prevent bone marrow suppression (multiple & antioxidant formula will contain E; check totals).

**Essential fatty acids/EFA's:**

omega-6 fatty acids such as gamma linolenic acid (GLA found in evening primrose/ borage/black currant/grape seed oil; 240-1440 mg/day) and omega-3 fatty acids such as EPA & DHA (max EPA; 300-600 mg/day); or combos like OmegaSyn (3/day); deficiencies can cause skin problems/fatigue/ immune dysfunction/dry skin & scalp.

**NAC (1800-5400 mg/day) & Glutathione (450-1500 mg)**

powerful antioxidant; critical to immune function; levels decline as HIV progresses; may slow progression.

**Zinc:**

25-50 mg/day in bioavailable form such as citrate or picolinate; deficiency common & causes skin problems, taste/smell disorders (multiple may have enough; toxicity possible at more than 100 mg/day long-term but only likely at very high levels; long-term use should be balanced with copper, 2-4 mg per day taken at different meal than zinc).

Nutrient supplementation can significantly affect symptomatology, often eliminating many symptoms such as the following (nutrients that may help eliminate that symptom are listed in parentheses): **fatigue** ($B_{2,}$ EFA's, C, E, magnesium, chromium, Coenzyme $Q_{10}$) **skin problems** (zinc, EFA's, A, beta carotene, $B_6$), **weight loss** (enteral and parenteral formulas, multiple nutrients), **loss of sense of smell or taste** (zinc, EFA's, potassium), **loss of appetite** (zinc, multiple nutrients), **certain types of cognitive dysfunction including memory loss and loss of ability to concentrate** ($B_2$), **some types of nerve pain** (biotin, $B_2$, choline, inositol, thiamine, $B_6$), **depression/anxiety** ($B_2$, $B_6$, zinc), **muscle cramps** (magnesium, calcium, E), etc.

All additions to your program should be made in consultation with a licensed health care practitioner qualified to monitor your progress.

For more information on all of the above plus many additional nutrients and other therapeutics that may be needed, depending on your clinical status and disease stage, see **Positively Well*: Living with HIV as a Chronic, Manageable, Survivable Disease.** This fact sheet is a brief overview of the type of approach to living with HIV that is described in depth in Dr. Lands' book (Underlined above), a practical guide to nutrition, drugs and therapeutic agents, energy therapies, psychoimmunity, and hope! To order the book, please call 800-542-8102, 9:00am to 5:00pm EST. Books can be sent via shipping service for quick delivery.

# BASIC SOURCES OF NUTRIENTS

### Vitamin A
**(retinol, beta-carotene)**
Fish liver oil
Liver, organ meats
egg yolk
Fortified milk, cheese
Butter, fortified margarine
Cantaloupe
Cherries
Apricots
Watermelon
Peaches
Fortified oatmeal
**Yellow or orange vegetables:**
winter squash
acorn squash
butternut squash
sweet potato
yams
pumpkin carrots
yellow turnips.
**Dark green vegetables:**
broccoli
spinach
kale
collard greens
turnip greens
peas

### Vitamin E
**(alpha-tocopherol)**
Safflower oil
Butter
Fortified margarines
Egg yolk
Liver
Wheat germ oil
Collard greens
Turnip greens
Spinach
Kale
Whole grains
Nuts

### Vitamin $B_{12}$
**(cyanocobalamin)**
Organ meats
Meats
Fish/seafood
Cheese
Eggs
Poultry
Tempeth

### Biotin
Liver
Organ meat
Molasses
Milk

### Copper
Whole grain cereal
Whole grain breads
Shellfish
Nuts
Organ meats
Eggs
Poultry
Dried beans / peas,
Spinach
Kale
Broccoli
Dried fruits
Mushrooms

### Vitamin C
**(ascorbic acid)**
Oranges
Tangerines
Grapefruit
Lemons
Limes
Cantaloupe
Strawberries
Kiwi
Green peppers
Tomatoes
Potatoes
Parsley
Broccoli
**Fresh green leafy vegetables:**
collard greens
turnip greens
spinach
kale

### Vitamin $B_6$
**(pyridoxine)**
Meats
Organ meats
Poultry
Fish
Egg yolks
Soybeans
Peanuts /walnuts
Tomatoes
Bananas
Avocado
Prunes
Potatoes
Cabbage
Cauliflower
**Dry beans / peas:**
pinto beans
kidney beans
split peas
lentils
black eyed peas
great northern beans
**Whole grain cereals:**
shredded wheat
bran
wheat germ/bran
Whole grain bread
whole wheat

### Iron
Liver, kidney
Organ meat
Beef, ham
Dried fruit, nuts
Lima beans
Dried beans/peas
Dark green leafy vegetables
Sardines, tuna, oysters,
Prune & tomato juice
Whole grain cereals/breads
Egg
Chicken
Strawberries
Blackberries
Brussel sprouts
Broccoli,
Winter squash
Pumpkin
Canned salmon

### Selenium
Liver
Kidney
Meats
Seafood
Whole grains

### Vitamin $B_1$
**(thiamine)**
Pork
Beef
Organ meats
Whole wheat
Whole grain products
Wheat germ
Brewer's yeast
Enriched cereals
Nuts
Milk
Avocados
Cauliflower
Spinach
Dried fruits
**Dry beans / peas:**
pinto beans
kidney beans
split peas
lentils
black eyed peas
great northern beans
black beans

### Folacin
**(folic acid)**
Whole grains
Wheat germ
Yeast
Organ meats
Kidney & lima beans Asparagus
Broccoli
Cauliflower
Green peas
Cabbage
Sweet potatoes
Orange juice
Cantaloupe
**Dark green vegetables:**
collard greens
turnip greens
kale
spinach

### Niacin
**(nicotinic acid)**
Organ meat
Meats
Peanuts
Milk
Eggs
Lentils
Split peas
Dry beans/peas
Whole grain bread
Whole grain cereal
Potatoes
Orange juice

### Calcium
Milk
Yogurt
Hard cheese
Cottage cheese
Dark green leafy vegetables
Broccoli
Oranges
Grapefruit
Sardines
Canned fish with bones
Dried beans/peas

### Vitamin $B_2$
**(riboflavin)**
Liver
Milk
Milk products
Oysters
Meat
Spinach
Kale
Collard greens
Turnip greens
Eggs
Tuna,
Salmon
Asparagus
Broccoli
Brussel sprouts
Mushrooms

### Vitamin D
**(cholecalciferol)**
Cod liver oil
Fish oil
Salmon, Herring, sardines
Egg yolks
Butter
Liver
Fortified milk

### Pantothenic acid
Liver
Organ meat
Fish
Chicken
Eggs
Cheese
Whole grain cereal / breads
Avocados
Cauliflower
Greens peas
Dried beans / peas
Nuts
Dates
Sweet potatoes

### Zinc
Oysters
Herring
Milk
Meat
Egg yolks
Whole grain

### Magnesium
Nuts, peanut butter
Lentils
Split peas
Whole grain cereals/breads
Soybeans
Seafood
Broccoli
Spinach
Collard, turnip & mustard greens

### Vitamin K
**(phylloquinone)**
**Dark green leafy vegetables:**
spinach
kale
turnip, collard, & mustard greens
broccoli

# VITAMINS: A BASIC PRIMER

Vitamins are naturally derived chemicals in food that have a very positive effect on our health and well-being. So far, 13 different vitamins have been identified as necessary for human nutrition—so necessary that we can not live without them. The following information provides a basic look at these critical building blocks to better health.

## What are vitamins?

Vitamins are organic compounds required by every part of the body to maintain health and prevent disease. They are classified as either fat-soluble or water-soluble.

### Fat-soluble vitamins

Vitamins A, D, E and K dissolve in fat and are found in the fatty parts of food and body tissues. They are stored in the body until needed, so it isn't necessary to consume them every day.

### Water-soluble vitamins

Vitamins C and the B complexes dissolve in water and are associated with the watery parts of food and body tissues. These vitamins are not stored by the body. Excess amounts are usually excreted in the urine and, therefore, should be provided in the diet on a regular basis.

## Where do vitamins come from?

Plants and animals produce vitamins. While some vitamins such as D and K can be produced within our bodies, the levels are not enough to meet our needs. The best way to ensure we take in sufficient amounts of these nutrients is to eat healthful and wholesome foods. Fruits and vegetables, whole grains, nuts and seeds, dairy products, seafood and organ meats (liver and kidney) eaten as part of a well-balanced diet, should provide all the vitamins needed. Supplements should be taken only upon the advice of a physician.

## How much do we need?

The U.S. Recommended Daily Allowances (U.S. RDAs) for vitamins, featured in the chart on the next page, are standards set by the Food and Drug Administration for nutrition labeling of foods. Based on recommendations established by the National Academy of Sciences, they specify four classes of daily vitamin intake for infants, children under four, adults and children over four, and pregnant or lactating women. The RDAs are considered adequate to meet the nutritional needs of the average healthy person. They provide a reasonable margin of safety for each vitamin.

However, age, sex, level of physical activity and environment all influence the need for vitamins. Eating less to reduce weight or eating too many refined foods can lead to temporary deficiencies; while stress, smoking, excessive alcohol consumption, pregnancy and breast feeding all increase the body's demands far vitamins and may also bring about temporary deficiencies.

## Can we take too many?

Overdosing on vitamins can cause serious side effects loss of coordination, nausea, rashes, diarrhea and fatigue. Excess amounts of the fat-soluble vitamins, stored in the body, can reach toxic levels. Even water-soluble vitamins, when taken to extreme, can be dangerous. The key is moderation and a well-balanced diet featuring a range of healthy, vitamin-rich foods.

# VITAMIN FACTS

## Vitamin A (Carotene)

**U.S. RDA: 5000 IU/day.**

**Best Sources:** Yellow or orange fruits & vegetables, green leafy vegetables, fortified oatmeal, liver, dairy products.

**Functions:** Formation and maintenance of skin, hair and mucous membranes; helps us see in dim light; bone and tooth growth.

**Deficiency Symptoms:** Night blindness, dry and scaly skin, frequent fatigue.

**Toxic?:** Yes, in high doses, but beta-carotene is nontoxic.

**Processing Tips:** Serve fruits and vegetables raw and keep covered and refrigerated. Steam veggies; broil, make or braise meats.

**Did You Know?:** Low fat and skim milks are often fortified with Vitamin A which is removed with the fat.

## Vitamin $B_1$ (Thiamine)

**U.S. RDA:** 1.5 mg/day.

**Best Source:** Fortified cereals and oatmeals, meats, rice and pasta, whole grains, liver.

**Functions:** Helps body release energy from carbohydrates during metabolism; growth and muscle tone.

**Deficiency Symptoms:** Heart irregularity, fatigue, nerve disorders, mental confusion.

**Toxic?:** No, high doses are excreted by the kidneys.

**Processing Tips:** Don't rinse rice or pasta before and after cooking. Cook in minimal water.

**Did You Know?:** Pasta and breads made of refined flours have $B_1$ added since it is lost in the milling process.

## Vitamin $B_2$ (Riboflavin)

**U.S. RDA:** 1.7 mg/day.

**Best Sources:** Whole grains, green leafy vegetables, organ meats, milk and eggs.

**Functions:** Helps body release energy from protein, fat and carbohydrates during metabolism.

**Deficiency Symptoms:** Cracks in corners of mouth, skin rash, anemia.

**Toxic?:** No toxic effects reported.

**Processing Tips:** Store foods in containers that light cannot enter; cook vegetables in minimal water; roast or broil meats.

**Did You Know?:** Most ready-to-eat cereals are fortified with 25% of the U. S. RDA for $B_2$.

## Vitamin $B_6$ (Pyridoxine)

**U.S. RDA:** 2 mg/day.

**Best Sources:** Fish, poultry, lean meats, bananas, prunes, dried beans, whole grains, avocados.

**Functions:** Helps build body tissue and aids in metabolism of protein.

**Deficiency Symptoms:** Convulsions, dermatitis, muscular weakness, skin cracks, anemia.

**Toxic?:** Long-term megadoses may cause nerve damage in hands and feet.

**Processing Tips:** Serve fruits raw or cook for shortest time in little water; roast or broil meats.

**Did You Know?:** Since $B_6$ aids in use of protein in the body the need for $B_6$ increases with protein intake.

### VITAMIN $B_{12}$ (COBALAMIN)

**U.S. RDA:** 6 mcg/day.

**Best Sources:** Meats, milk products, seafood.

**Functions:** Aids cell development, functioning of the nervous system and the metabolism of protein and fat.

**Deficiency Systems:** Anemia, nervousness, fatigue, and, in some cases, neuritis and brain degeneration.

**Toxic?:** No toxic effects reported.

**Processing Tips:** Roast or broil meat and fish.

**Did You Know?:** Vegetarians who don't eat any animal products may need a supplement.

### BIOTIN

**U.S. RDA:** 0.3 mg/day.

**Best Sources:** Cereal/grain products, yeast, legumes, liver.

**Functions:** Involved in metabolism of protein, fats and carbohydrates.

**Deficiency Symptoms:** Nausea, vomiting, depression, hair loss, dry, scaly skin.

**Toxic?:** No toxic effects reported.

**Processing Tips:** Storage, processing & cooking do not appear to affect this vitamin.

**Did You Know?:** Biotin deficiency is extremely rare in the U.S.

### FOLIATE (FOLACIN, FOLIC ACID)

**U.S. RDA:** 0.4 mg/day.

**Best Sources:** Green leafy vegetables, organ meats, dried peas, beans and lentils.

**Functions:** Aids in genetic material development and involved in red blood cell production.

**Deficiency Symptoms:** Gastrointestinal disorders, anemia, cracks on lips.

**Toxic?:** Some evidence of toxicity in large doses.

**Processing Tips:** Store vegetables in refrigerator and steam, boil or simmer in minimal water.

**Did You Know?:** Deficiencies can occur in premature infants and pregnant women.

### NIACIN

**U. S. RDA:** 20 mg/day.

**Best Sources:** Meat, poultry, fish, enriched cereals, peanuts, potatoes, dairy products, eggs.

**Functions:** Involved in carbohydrate, protein and fat metabolism.

**Deficiency Symptoms:** Skin disorders, diarrhea, indigestion, general fatigue.

**Toxic?:** Nicotinic acid form should be taken only under doctor's care.

**Processing Tips:** Roast or broil beef, veal, lamb and poultry. Cook potatoes in minimal water.

**Did You Know?:** Niacin is formed in the body by converting an amino acid found in proteins.

### PANTOTHENIC ACID

**U.S. RDA:** 10 mg/day.

**Best Sources:** Lean meats, whole grains, legumes, vegetables, fruits.

**Functions:** Helps in the release of energy from fats and carbohydrates.

**Deficiency Symptoms:** Fatigue, vomiting, stomach stress, infections, muscle cramps.

**Toxic?:** No toxic effects reported.

**Processing Tips:** Eat fruits and vegetables raw.

**Did You Know?:** It is believed some pantothenic acid is produced in the G.I. tract.

### VITAMIN C (ASCORBIC ACID)

**U.S. RDA:** 60 mg/day.
**Best Sources:** Citrus fruits, berries, and vegetables - especially peppers.
**Functions:** Essential for structure of bones, cartilage, muscle and blood vessels. Also helps maintain capillaries and gums and aids in absorption of iron.
**Deficiency Symptoms:** Swollen or bleeding gums, slow wound healing, fatigue/ depression, poor digestion.
**Toxic?:** Intakes of one gram or more can cause nausea, cramps and diarrhea.
**Processing Tips:** Do not store or soak fruits and vegetables in water. Refrigerate juices and store only 2-3 days.
**Did You Know?:** Smokers may benefit from an increased intake of Vitamin C.

### VITAMIN D

**U.S. RDA:** 400 IU/day.
**Best Sources:** Fortified milk, sunlight, fish, eggs, butter, fortified margarine.
**Functions:** Aids in bone and tooth formation; helps maintain heart action and nervous system.
**Deficiency Symptoms:** In children: rickets and other bone deformities.
In adults: calcium loss from bones.
**Toxic?:** High intakes may cause diarrhea & weight loss.
**Processing Tips:** Storage, processing & cooking do not appear to affect this vitamin.
**Did You Know?:** Sunlight starts Vitamin D production in the skin.

### VITAMIN E

**U.S. RDA:** 30 IU/day.
**Best Sources:** Fortified & multi-grain cereals, nuts, wheat germ, vegetable oils, green leafy vegetables.
**Functions:** Protects blood cells, body tissue and essential fatty acids from harmful destruction in the body.
**Deficiency Symptoms:** Muscular wasting, nerve damage, anemia, reproductive failure.
**Toxic?:** Relatively nontoxic.
**Processing Tips**: Store in air-tight containers away from light.
**Did You Know?**: Most fortified cereals have 40% of the RDA.

### VITAMIN K

**U.S. RDA**: 30 IU/day.
**Best Sources:** Green leafy vegetables, fruit, dairy and grain products.
**Functions:** Essential for blood clotting functions.
**Deficiency Symptoms:** Bleeding disorders in newborn infants and those on blood-thinning medications.
**Toxic?:** Not toxic as found in food.
**Processing Tips:** Store in containers away from light.
**Did You Know?:** Vitamin K is also formed by bacteria in the colon.

# BASIC FOOD -SAFETY PRINCIPLES FOR AVOIDING FOOD-BORN ILLNESS

Although this information may seem overwhelming, there are methods to help ensure your food is safe. The following section contains some basic tips to remember for the prevention of food-borne illnesses.

### When shopping:

- ✖ Don't buy rusted, dented, or bulging cans or jars.
- ✖ Think twice about buying salads (potato, egg, chicken, macaroni) at supermarket delis.
- ✖ Avoid soft ripened cheeses such as brie, feta, and aged cheeses

- ✔ Refrigerate frozen items and perishables as soon as possible.
- ✔ Only buy pasteurized milk and shelled eggs.

### When storing foods:

- ✔ Keep foods refrigerated as long as possible, avoid lengthy stays at room temperatures.
- ✔ Keep hot food hot and cold food cold.
- ✔ Wrap and cover foods in the refrigerator. Use air-tight containers when possible.
- ✔ Store hot leftovers in a shallow, small container. Reheat until hot to touch through out, or to 165°F.

- ✖ Avoid overcrowding a refrigerator or freezer, this can decrease air circulation.
- ✖ Don't keep Leftovers for more than three days. **When in doubt, throw it out!**
- ✖ Don't consume moldy or spoiled foods.

### When handling foods:

- ✔ Wash hands thoroughly and frequently. Don’t use the same utensils (knives and cutting boards) to cut raw meats such as chicken and then chop raw vegetables.
- ✔ Scrub vegetables and fresh produce to remove visible dirt.
- ✔ Cook meats, poultry and seafood thoroughly. The (FDA) recommends that meat be cooked to an internal temperature of 160°F at the thickest point. Poultry should be cooked to 185°F.
- ✔ Wash cloth towels used in the kitchen after one day’s use.
- ✔ Between handling and preparing food items, wash utensils and hands.

- ✖ Don’t use wooden cutting boards.
- ✖ Don’t allow juices from raw products to drip on foods.
- ✖ Never thaw frozen foods by letting them sit out at room temperature.
  - ✔ **Safe methods of thawing include**
    - a. thawing in the refrigerator.
    - b. thawing under cold running water.
    - c. thaw/defrost in microwave.

### Special precautions with eggs:

- ✔ Use eggs graded A or higher.
- ✔ Leave eggs in the original container in the refrigerator; the egg rack in the door may have higher temperatures.

- ✖ Don’t use cracked eggs.
- ✖ Don’t serve raw eggs and foods containing raw eggs’ (such as Caesar salads, Hollandaise sauce, homemade ice cream, homemade egg nog, and homemade mayonnaise).

### When eating out:

- ✔ Inquire about preparation methods. (Are raw eggs used in salad dressings?)
- ✔ Ask for food to be thoroughly cooked
- ✔ Notice if creamer containers are left sitting on tables. If so, ask for a new one

# HIV/AIDS AND FOOD SAFETY

## FOOD SAFETY

**Consider all raw animal products contaminated**

1. Cook all meat, poultry, eggs, seafood thoroughly - no pink meats, runny yolks and no steamed seafood
2. Consume only pasteurized milk products

**Store foods at proper temperature**

1. Do not let cold food sit at room temperature for more than 2 - 4 hours
2. Cold foods below 40 F
3. Hot foods above 140 F

**Keep clean hands and a clean kitchen**

1. Wash hands often
2. Use one cutting board for raw meats and one for cooked foods - wash after each food

## WATER SAFETY

1. Boiled tap water
2. Bottled distilled water
3. NSF approved water filter

# CRYPTOSPORIDIA AND THE WATER SUPPLY [8]

Cryptosporidia are single-cell intestinal parasites that cause chronic profuse diarrhea, dull upper abdominal cramps and severe weight loss. This infection can be fatal for people with severely suppressed immune systems. Removing Cryptosporidia from water requires a filter that removes particles smaller than two microns (less than one ten-thousandth of an inch).

## Safer Water Sources

- Distilled water is safe.
- Boil all tap water for at lest five minutes to make the drinking water safe.
- Lemon or other flavorings may be added to improve the taste. Pour into clean dry containers. Dishes, silverware, pots and pans may be washed with tap water as long as they are dry before they are used.
- Some bottled "spring water", is filtered well enough to trap cryptosporidiosis. The following brands report that they use safe filters: Deer Park, Great Bear, Naya, Poland Springs, Saratoga, Vivanti, Wissahichon.
- Wash all fresh fruits and vegetables with boiled (and cooled), distilled or properly filtered water before eating raw.
- Use only boiled, distilled or properly filtered water to make ice cubes, dilute fruit juices from concentrate and brush your teeth. Beware of beverages and ice cubes at restaurants, where they are usually made with tap water.
- Commercially bottled soft drinks and seltzers are considered safe. Bottled juices are safe if they have been pasteurized and do not require refrigeration before opening.
- Milk is safe if pasteurized.
- Be careful not to swallow pool or bath water.

## Home Water Filtration Systems

Some home water filtration systems can separate out Cryptosporidia. The following companies claim that their products include sufficiently fine filters:

**Multi-Pure Drinking Water Systems**, 21339 Nordhoff Street, Chats worth, CA 91311. New York City contact: Krae van Sickle, 212/242-2317 or 516/329-9205

Multi-Pure's models are tested and certified by the EPA and the NSF (National Sanitation Foundation). Prices range from $189.95 to $329.95.

**Everpure Water Treatment Products,** 660 N. Blackhawk Drive, Westmont, IL 60559, 800/323-7873. New York City contact: Lee Hamer, 212/242-1787.

Everpure's models are certified by the NSF to remove particles five microns in size. Prices range from $150 to $500.

**Neolife**, 155 West Eighty-first Street, #6H, New York, New York 10024, 212/874-6640. The Neolife Water Dome removes particles 0.4 microns and larger. Counter top units cost $199.50 and under counter units $387.50.

**Equinox**, Tres Jordan, 212/421-4247

Equinox filters particles down to one micron in size.

***Above all, don't forget to wash and dry your hands before you eat or drink!***

# ORGANISMS THAT CAN BUG YOU

## DISEASE AND ORGANISM THAT CAUSES IT: BACTERIA

**Botulism/Botulinurn toxin (produced by Clostridium botulinum bacteria)**

**Source:** Spores of these bacteria are widespread. But these bacteria produce toxin only in an anaerobic (oxygen less) environment of little acidity. Found in a verity of canned foods, such as corn, green beans, soups, beets, asparagus, mushrooms, tuna, and liver pate'. Also in luncheon meats, ham, sausage, stuffed eggplant, lobster and smoked and salted fish

**Symptoms:** Onset: Generally 4-36 hours after eating. Neuro-toxic systems, including double vision, inability to swallow, speech difficulty, and progressive paralysis of the respiratory system. Get medical help immediately. Botulism can be fatal.

**Campylobacteriosis (Campylobacter jejuni)**

**Source:** Bacteria on poultry, cattle, and sheep can contaminate meat and milk of these animals. Chief food sources: raw poultry, meat and unpasteurized milk

**Symptoms:** Onset: Generally 2-5 days after eating. Diarrhea, abdominal cramping, fever, and sometimes bloody stools. Lasts 7-10 days

**Listeriosis (Listeria monocytogenes)**

**Sources:** Found in soft cheese, unpasteurized milk, imported seafood products, frozen cooked crab meat, cooked shrimp, and cooked surimi (imitation shellfish). The listeria bacteria resist heat, salt, nitrite, and acidity better that many other micro-organisms. They survive and grow at low temperatures.

**Symptoms:** Onset: Generally from 7-30 days after eating, but most symptoms have been reported 48-72 hours after consumption of contaminated food. Fever, headache, nausea, and vomiting. Primarily affects pregnant women and their fetuses, newborns, the elderly, people with cancer and those with impaired immune systems. Can cause fetal and infant death.

**Perfringens food poisoning (Clostridium perfringens)**

**Source:** In most instances caused by failure to keep food hot. A few organisms are often present after cooking and multiply to toxic levels during cool down and storage of prepared foods. Meats and meat products are the foods most frequently implicated. These organisms grow better than other bacteria between 120-130 F. So gravies and stuffing must be kept above 140 F.

**Symptoms:** Onset: Generally 8-12 hours after eating. Abdominal pain and diarrhea, and sometimes nausea and vomiting. Symptoms last a day or less and are usually mild. Can be more serious in older or debilitated people.

**Salmonellosis (salmonella bacteria)**

**Source:** Raw meats, poultry, milk and other dairy products, shrimp, frog legs, yeast, coconut, pasta, and chocolate are most frequently involved.

**Symptoms:** Onset: Generally 6-48 hours after eating. Nausea, abdominal cramps, diarrhea, fever, and headache. All age groups are susceptible, but symptoms are most severe for elderly, infants and infirm.

## DISEASE AND ORGANISM THAT CAUSES IT: BACTERIA, CONT'D

**Shigellosis bacillary dysentery (Shigella bacteria)**

**Source:** Found in dairy products, poultry and potato salad. Food becomes contaminated when a human carrier does not wash hands and then handles liquid or moist food that is not cooked thoroughly afterwards. Organisms multiply in food left at room temperature.

**Symptoms:** Onset: 1-7 days after eating. Abdominal cramps, diarrhea, fever, sometimes vomiting, and blood, pus or mucus in stools.

**Staphylococcal food poisoning**
**Staphylococcal enterotoxin (produced by Staphylococcus aureus bacteria)**

**Source:** Toxin produced when food contaminated with the bacteria is left too long at room temperature. Meats, poultry, egg products, tuna, potato and macaroni salads, and cream-filled pastries are good environments for these bacteria to produce toxin.

**Symptoms:** Onset: Generally 30 minutes - 8 hours after eating. Diarrhea, vomiting, nausea, abdominal pain, cramps, and prostration. Lasts 24 - 48 hours. Rarely fatal.

**Vibrio infection (Vibrio vulnificus)**

**Source:** The bacteria live in coastal waters and can infect humans either through open wounds or through consumption of contaminated seafood. The bacteria are most numerous in warm weather.

**Symptoms:** Onset: Abrupt. Chills, fever, and/or prostration. At high risk are people with liver conditions, low gastric (stomach) acid, and weakened immune systems.

## DISEASE AND ORGANISM THAT CAUSES IT: PROTOZOA

**Amoebiasis (Entamoeba histolyica)**

**Source:** Exist in the intestinal tract of humans and are expelled in feces. Polluted water and vegetables grown in polluted soil spread the infection.

**Symptoms:** Onset: 3 - 10 days after exposure. Severe cramps pain, tenderness over the colon or liver, loose morning stools, recurrent diarrhea, loss of weight, fatigue, and sometimes anemia.

**Giardiasis (Giardia lamblia)**

**Source:** Most frequently associated with consumption of contaminated water. May be transmitted by uncooked foods that become contaminated while growing or after cooking by infected food handlers. Cool, moist conditions favor organism's survival.

**Symptoms:** Onset: 1 - 3 days. Sudden onset of explosive watery stools, abdominal cramps, anorexia, nausea, and vomiting. Especially infects hikers, children, and institutionalized patients.

## DISEASE AND ORGANISM THAT CAUSES IT: VIRUS

**Hepatitis A virus**

**Source:** Mollusks (oysters, clams, mussels, scallops, and cockles) become carriers when their beds are polluted by untreated sewage. Raw shellfish are especially potent carries, although cooking does not always kill the virus.

**Symptoms:** Onset: begins with molasses, appetite loss, nausea, vomiting, and fever. After 3 - 10 days patient develops jaundice with darkened urine. Severe cases can cause liver damage and death.

# FOOTNOTES

1. by Shelly Moorwessel, MMSc, RD, LD
   Grady Health System Infectious
   Disease Program (404) 616-9797

2. by Charmaine Frederick, RD
   Caremark Homecare, November 1989

3. by Sonny Magill, 1995

4. by Charmaine Frederick, RD
   Caremark Homecare, November 1989

5. Grady Health System
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   Medical Nutrition Therapy
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8. Gay Men's Health Crisis
   *Treatment Issues,* 1995

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Grady Health System Infectious Disease Program and Sonny Magill, AIDS Survival Project Volunteer.
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# OPPORTUNISTIC INFECTIONS

FOR MORE INFORMATION ABOUT TREATMENT OPTIONS, PLEASE REFER TO THE SECTION OF THE WORKBOOK TITLED "TREATMENT STRATEGIES."

# What You Need to Know About Opportunistic Infections

There are two very important things to keep in mind when you look through this section of the *Operation: Survive!* workbook:

- ☞ You wont get all, or maybe even any, of the illnesses described in this chapter
- ☞ An ounce of prevention really is worth a pound of cure

We recognize that the information in this chapter may feel quite overwhelming. That is why it is so important to keep it in perspective. We aren't trying to frighten you, but by being aware of what's out there, you might just be able to prevent yourself from getting an illness that compromises your health. This chapter will begin with brief discussions of the most common opportunistic infections and conclude with the Project Inform Opportunistic Infection chart. If you are seeking information about a specific opportunistic infection that you don't see listed here, please visit our Treatment Resource Center at 828 W. Peachtree Street for more comprehensive information or call us at (404) 874-7926.

Opportunistic Infections are called that because they take advantage of an opportunity (i.e. a weakened immune system) to take hold and wreak havoc. This is another reason it is important to keep your immune system in as good a shape as possible (*please see the Treatment Strategies section of this workbook).* Most opportunistic infections are preventable, if you know what to look for and how to avoid them in the first place. It is with this in mind that we offer the following pages.

The information in this workbook is intended as a tool to help you take care of yourself and to better work with your health care provider. Persons living with HIV/AIDS, as well as their medical advisors, must recognize that treatment issues relating to HIV/AIDS are complex and that information regarding treatments may change from day to day. It is helpful for individuals to gather as much information as possible concerning a particular therapy or treatment before making a decision whether or not to use such treatment(s) or therapy. Such decisions need always to be made in consultation with a health care provider who is knowledgeable about HIV/AIDS and the therapies or treatments in question. We typically see a substantial difference in the treatment(s) prescribed by experienced health care providers with established HIV practices and those prescribed by health care providers with less HIV experience. If you need help locating a health care provider, please call an AIDS Survival Project peer counselor at (404) 874-7926. As well, there may be times when you will need to educate your health care provider about new or experimental therapies that they haven't yet tried, or maybe even heard about.

AIDS Survival Project does not recommend, advocate or endorse the use of any particular treatment, therapy, or course of action described in this workbook. AIDS Survival Project therefore does not accept the risk of, or responsibility for, any damages, costs or consequences of any kind whatsoever which may arise or result, either from use or reliance on the information contained herein, or due to any errors contained herein. Persons relying on the information contained in this workbook must do so at their own discretion.

# CANDIDIASIS

Candida is a fungus which can cause infection in the mouth, esophagus, and vagina. When the mouth is infected, the resulting white patches on the palate, throat, tongue and gums are called thrush. This must be distinguished from oral hairy leukoplakia (caused by Epstein-Barr Virus) which is usually found on the side of the tongue. Thrush may cause discomfort and difficulty in eating but is not usually acutely painful. If the candida spreads to the esophagus (the tube leading from the mouth to the stomach) difficulty in swallowing may occur. In women, itching, burning, and a discharge are characteristics of vaginal candidiasis. Candida infections are usually treated presumptively (based on appearance).

Treatment for mild infections are usually topical - creams for vaginal infections, lozenges or liquid antifungal drugs for thrush. Esophageal infection requires treatment with ketoconazole, fluconazole, or itraconazole. These oral drugs are relatively safe when used for a short time. If the candida infection is persistent or reoccurs frequently, lifetime use of oral medication may be needed. Since candida infections are usually easily treated and resistance may develop to oral drugs, oral prophylaxis is not recommended.

Daily use of lozenges or liquid antifungal drugs usually prevent thrush. Women may want to consider douching with yogurt containing active culture to prevent vaginal yeast infections.

# CERVICAL DISEASE

**Please also see the Women & HIV section in this workbook**

Women with HIV (especially those with multiple sexual partners, a history of smoking, and use of oral contraceptive pills) are at a higher risk of developing cancer of the cervix. This risk is probably related to an infection of the cervix by human papilloma virus. Routine pelvic exams and pap smears can help detect the infection early-before it leads to cancer. The earliest stages of the disease are usually asymptomatic. Occasionally bleeding between periods and bleeding after sex are early symptoms. If an abnormal pap smear shows signs of cervical intraepithelial neoplasia (CIN), an exam using a colposcope can be used to examine the cervix. CIN is not cancer but can lead to cancer if not treated. Since smoking is known to increase the risk of acquiring CIN, women with HIV are encouraged to quit.

# CRYPTOCOCCUS

Cryptococcus is a fungus which enters the body through the lungs. When the immune system is healthy, the infection is readily contained. In HIV infected individuals, the fungus enters the bloodstream and may infect the meninges (the covering over the brain). Headaches, fever, nausea and changes in mental functions (i.e. thinking, speaking) may be seen in some individuals with meningitis. The fungus can also infect internal organs and the skin.

A blood test for cryptococcus is a good indicator of exposure to the fungus. Those who test positive for cryptococcus in the blood must have a spinal tap to rule out infection of the meninges.

When cryptococcal meningitis is suspected, a brain scan is done to rule out other causes of headaches. If the scan is normal, a spinal tap may be done safely. Meningitis usually does not occur until the T cells are below 100.

If cryptococcus is found in the spinal fluid, treatment is begun with **amphotericin.** This drug has many side effects, including fevers, chills, nausea, and kidney damage. After amphotericin is given for a specified time, fluconazole must be taken for the rest of one's life. The cryptococcal meningitis cannot be completely cured and will reoccur if the fluconazole is stopped.

For those who test positive for cryptococcus in the blood but do not have the fungus in the spinal fluid, fluconazole is given daily to prevent the fungus from infecting the brain.

Some practitioners recommend fluconazole for prevention of cryptococcal disease. The drug is relatively safe but may cause liver problems (rarely). The chance of getting meningitis is directly related to a positive blood test for cryptococcus. So those with negative blood tests do not need prophylaxis. The use of prophylaxis is highly controversial. The high cost of the medicine and the chance of breeding resistant fungi are the main arguments against using fluconazole for prophylaxis.

# CRYPTOSPORIDIUM

Cryptosporidium is a parasite which causes intestinal infections in those with AIDS. Watery diarrhea, stomach cramps, and gas are the main symptoms. Cryptosporidium can also infect the liver and bile ducts. Those with CD4+ T cells below 200 are at the highest risk. Cryptosporidium may cause diarrhea in non-HIV infected individuals, but it is usually well controlled by a healthy immune system. In people with HIV, the diarrhea may be persistent. There are no drugs currently that can completely eliminate the infection.

There have been recent developments of drugs to treat cryptosporidium including Nitazoxanide (NTZ), and Humatin, an antibiotic which can eliminate a large number of organisms, but is not always effective. Atovaquone (Mepron) also seems to have some activity against cryptosporidium. Additional treatment is aimed mainly at reducing the amount of diarrhea with medications like Lomotil, Immodium AD, Kaopectate, Pepto-Bismal and Sandostatin injections. It is important to consume a lot of fluid in order to replace that lost in the diarrhea.

# CYTOMEGALOVIRUS (CMV)

CMV is a member of the herpes virus family. Symptomatic infection in those with HIV is most often due to reactivation of virus already in the body. When T cells fall below 50-100, CMV can cause infection of the eye (retinitis), esophagus (esophagitis), gastrointestinal tract, liver, and lungs.

## RETINITIS:

The retina receives images in the form of light and transmits them to the brain via the optic nerve. Retinitis is usually painless but can cause blurred vision, floaters, blind spots, and flashing lights. Any change in vision must be reported immediately to your doctor since early treatment of CMV will lessen the chance of total loss of vision. Monthly exams by your doctor may pick up signs of CMV, even before symptoms appear. CMV most often causes hemorrhage (bleeding) in the retina which may be seen during the opthalmoscopic exam. Treatment of retinitis involves lifetime therapy with one of several drugs:

**1. Ganciclovir (DHPG)**

**A) Infusion:**

Given twice a day for two weeks (induction dose) and then once daily (usually five times a week) for life. The major side effect is granulocytopenia (lowering of a type of white blood cell). AZT should be stopped while on ganciclovir since both may cause granulocytopenia.

**B) Oral:**

A capsule form of ganciclovir is the first oral drug to be approved for the treatment of CMV retinitis. Oral ganciclovir is an attractive option for some individuals since it avoids daily intravenous therapy. However, because the amount of ganciclovir in the body is less after oral than IV treatment, it involves some additional risk of disease progression, and is not the best therapy if CMV retinitis is immediately sight-threatening or rapidly progressive. To provide adequate amounts of drug to control the virus, it is essential to take the entire daily dose faithfully.

If you do not currently have active CMV disease, you may want to consider oral ganciclovir as a preventative. Oral ganciclovir can reduce the incidence of CMV retinitis. In one study where the patients had CD4 counts of about 20, oral ganciclovir reduced the incidence of CMV disease by half.

**C) Implants:**

Results of the ganciclovir eye implant studies are very good so far, with better results for CMV Retinitis than with the infusion therapy. However, infusion with ganciclovir can prevent systemic infections (i.e. lungs, intestinal tract, etc.) whereas the implant cannot. These implants are done in Atlanta. For more information call the office of Dr. Ron Martin at (404) 248-4815 (Debbie Gibbs can help you).

**D) Intraocular Injections:**

This is done by injecting medicine directly into the eye with a very small needle. Administration of ganciclovir directly into the eye reduces the risk of side effects caused by drug actions elsewhere in the body (primarily bone marrow suppression). However, like the implants mentioned above, intraocular injections do not protect the other eye or other organs which can also be affected by CMV.

**2. Foscarnet:**

This drug also requires “induction” doses for two weeks and lifetime “maintenance” therapy. The main side effect is kidney failure. This drug is used if a person cannot tolerate ganciclovir or if the retinitis fails to improve with ganciclovir.

**3. Cidofovir:**

This drug is administered intravenous on a weekly or bi-weekly basis.

**Esophagitis:**

This is usually painful. Severe pain on swallowing or difficulty swallowing are the main symptoms.

**Gastrointestinal tract:**

Involvement of the GI tract is usually manifested by diarrhea and abdominal pain, fever, and wasting.

# Guide to CMV Management [1]

As more therapies become available for the treatment of CMV retinitis (CMV in the eye), it becomes more essential to weigh the risks and benefits of all the different options. Old, new, and soon-to-be-approved treatment options differ in their usefulness for different CMV-related conditions. In addition, their impact on quality of life and in drug-related side effects differ greatly. It is possible that some approaches may prolong survival more so than others, but due to the difficulty of conducting the large trials needed in people with advanced disease - the only place where CMV is a major problem - this effect may never be clearly understood. Thus, each individual must face the prospect of choosing a therapy based on factors such as quality of life, risk of side effects, risk of wider spread of the infection, and more or less frequent need for additional therapy. Though not clearly documented, it is possible that new, more powerful treatments for HIV disease may themselves improve the effect of treatment for CMV infections.

## Available Therapies

The most common treatment for CMV disease is daily intravenous (in the vein) infusions of ganciclovir (Cytovene) or foscarnet (Foscavir). An oral form of ganciclovir is sometimes used for maintenance therapy (after a course of intravenous therapy) and can be used for prevention (prophylaxis) of CMV disease. These options are now joined by the ganciclovir implant (Vitrasert), approved by the FDA. Another drug, intravenous (IV) cidofovir (formerly known as HPMPC and also known as Vistide) will likely soon join the fray. A number of other therapies for CMV retinitis in clinical development include:

- Intravitreal cidofovir, a version of cidofovir injected directly into the eye;
- MSL 109, a monoclonal antibody administered intravenously;
- ISIS 2922, an antisense product designed to be injected directly into the eye;
- Lobucavir, an oral drug (taken by mouth, as a pill, rather than as an injection or infusion);
- Glaxo-Wellcome 1263. Another oral drug.

## Systemic vs. Localized Therapy

One of the most pressing questions for the treatment of CMV retinitis is whether localized therapy (treating a specific site, like the eye) is sufficient or superior to systemic (whole body) therapy. Since CMV disease can effect the entire body, many physicians believe that some form of systemic therapy is required. Others believe that only CMV retinitis warrants constant treatment and that outbreaks of CMV elsewhere in the body can be handled if and when they occur. All IV and oral drugs are considered systemic whereas the ganciclovir implant, intravitreal cidofovir and ISIS 2922 are “local” therapies, only treating CMV in the eye. The potential benefit of systemic therapy is that they will provide protection against CMV disease spreading into the other eye or into other parts of the body. However, this comes at a high cost, as all the IV drugs currently available can cause severe side effects and drug interactions. Systemic ganciclovir suppresses the bone marrow, while foscarnet and cidofovir can be very hard on the kidneys. Large amounts of drug are required to make sure the drug crosses the blood/eye barrier to have an effect against CMV retinitis. Typically, excessive amounts of drug must be used systemically to reach adequate levels inside the eye. Both foscarnet and IV ganciclovir require infusions daily and the insertion of a permanent catheter into a major artery. Such catheters bring with them a high risk of bacterial infections, such as sepsis, which can be difficult to treat in immunosuppressed people. Foscarnet also requires long, slow infusion times. IV cidofovir has some advantages in that it requires in fusion only once every other week, thereby eliminating the need for a surgically implanted catheter. The oral formulation of ganciclovir, while still a systemic therapy, eliminates the need for a catheter. However, it is not well absorbed and large amounts of drug are required. Because blood levels of ganciclovir are much lower when the drug is taken orally rather than IV, it doesn't work quite as well and there is some concern that this may lead to more rapid development of ganciclovir resistance and possible cross-resistance with other anti-CMV drugs (making those drugs ineffective in treating CMV).

The advantages of local therapy include a much improved quality of life and greatly reduced risk of side effects. Ocular (eye) implants of ganciclovir are inserted once every six to eight months. Intravitreal injections occur more frequently but are still less burdensome than daily infusions and the constant risks associated with catheters and systemic treatment. Both approaches also seem to suppress disease in the eye much longer than the standard IV ganciclovir or foscarnet treatments. The only real question about their use is the risk of CMV outbreaks elsewhere in the body. Clinical trials have so far failed to quantify this risk.

### COMMENTARY

A growing number of researchers and physicians believe the most effective and least invasive way of treating CMV retinitis may be to use a local therapy for the retinitis in combination with an oral therapy (although IV cidofovir may also play an important role in this regard due to its infrequent dosing). In theory this approach combines the high effectiveness and good quality of life associated with local therapy along with a reasonable level of protection against CMV out breaks elsewhere in the body. Some studies are already underway to deter mine if this is the overall best way of treating CMV retinitis.

Prophylaxis (preventing) CMV has been a hotly debated topic because of conflicting study results (for a complete review of these results, please refer to *PI Perspective* 16 and 17). One of the fears around CMV prophylaxis is that if someone does develop CMV while on those therapies, then their treatment options are severely limited as a result of resistance and cross-resistance to other CMV therapies. However, this does not appear to be the case based on recently released preliminary results. The issue of whether someone should prophylax against CMV is still unresolved. Studies need to be conducted to determine if we currently have the technology to predict if someone is at risk of developing CMV disease. New information on resistance to CMV therapies indicate that people who are resistant to ganciclovir are more at risk of developing resistance to foscarnet. Additionally, if people are resistant to both ganciclovir and foscamet, then they are more at risk of developing resistance to cidofovir.

People who have sight-threatening CMV retinitis should consider aggressive therapy such as a ganciclovir implant in addition to systemic IV therapy. People who do not have sight-threatening CMV retinitis may be able to use therapies which allow for a better quality of life such as initial therapy with IV drugs and subsequent maintenance with oral or local therapy. While issues of resistance add complexities to the decision making process, people should discuss these issues with their physicians and determine a course of therapy which meets their needs.

# Options for Treating CMV Retinitis

| Therapy | Advantages | Disadvantages |
|---|---|---|
| *IV ganciclovir*<br>(systemic)<br>**[Cytovene]** | Physicians have the most experience with this drug; should prevent CMV from spreading elsewhere | Immunosuppressive and can cause many possible drug interactions; poor quality of life; requires surgically implanted catheter for twice daily infusions; risk of bacterial infections |
| *IV foscarnet*<br>(Systemic)<br>**[Foscavir]** | Physicians have experience using this drug; should prevent CMV from spreading elsewhere. | Requires careful monitoring due to side effects; poor quality of life; requires surgically implanted catheter with risk of bacterial infection; may have overlapping toxicity with cidofovir. |
| *Oral ganciclovir*<br>(systemic)<br>**[Cytovene]** | Should prevent CMV from spreading elsewhere; improved quality of life. | Requires large amounts of drug; may be less effective and may contribute to more rapid development of resistance. |
| *IV cidofovir*<br>(systemic)<br>**[Vistide]** | Should prevent CMV from spreading elsewhere; somewhat improved quality of life. | Must be taken with probenecid to minimize side effects; possibility of drug interactions between probenecid and commonly used HIV medications; may have overlapping toxicity with IV foscarnet. |
| *Ganciclovir implants*<br>(localized)<br>**[Vitrasert]** | Significantly increases time before relapse; greatly improved quality of life; no risk of systemic side effects; no need for catheters and risk of bacterial infections. | Will not prevent CMV from spreading else where; fewer physicians have experience with this device; may cause an increased risk of retinal detachment. |
| *Intravitreal cidofovir*<br>(localized)(not yet approved) | Infrequent direct injection into the eye; improved quality of life. | Will not prevent CMV from spreading elsewhere; optimal frequency of injections not yet known; high doses may lead to irreversible toxicity; may cause an increased risk of retinal detachment. |
| *MSL 109*<br>(localized) (in clinical trials only) | May increase time to relapse. | Must be used in combination with other therapies. |

# Checking for Vision Problems

The Amsler grid can help people determine if vision problems exist or are getting worse. A person with no visual difficulty can see all lines on the chart clearly. If a person sees blind gaps, dark spots, or wavy lines, then **immediate medical attention is warranted.**

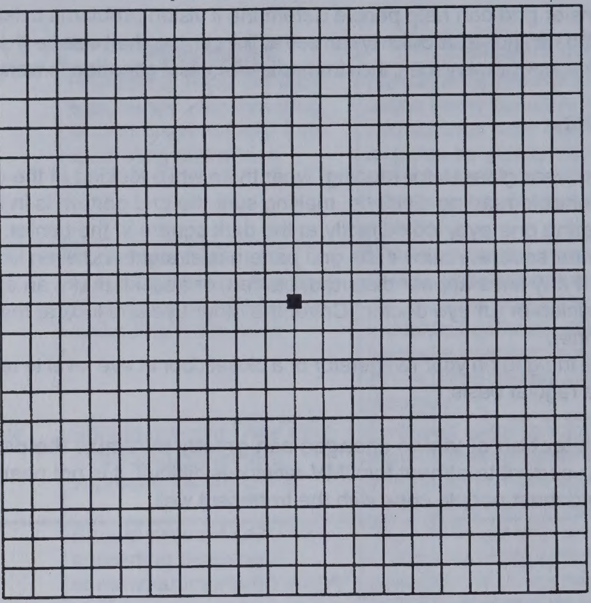
### To use the grid:

1. If you wear glasses for reading, wear them while looking at the grid. Place the grid at a comfortable reading distance, making sure the grid pattern is in focus.
2. Covering one eye, look directly at the dark square in the center. While looking only at the center square, notice if the grid pattern is straight and even like a piece of graph paper. If any lines appear distorted, blurred, or absent, make an appointment with your physician or an eye doctor. Cover the other eye and look at the grid again in the same manner.
3. Place the grid on your refrigerator or a closet door at eye level to remind yourself to check it on a regular basis.

**Early detection of vision changes can greatly minimize the damage done by CMV.** Although current treatment for CMV retinitis is difficult, it is not nearly as difficult as going blind, and most people cope with the treatment well.

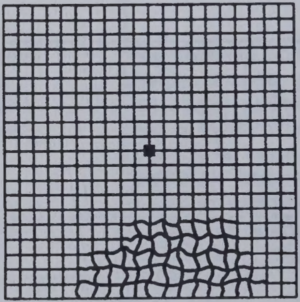
# CMV Retinitis

## AMSLER GRID

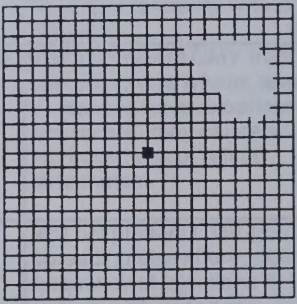


1991 Syntex Laboratories, Inc. Palo Alto, CA 94304

## ABNORMAL AMSLER GRIDS



Example of Distortion



Example of an Area Missing

**A suggestion:**
Post the Grid in some handy place such as next to your bathroom mirror or on the refrigerator; that way, you'll be reminded to check your vision every day.

**Important reminder:**
If you notice any vision changes, such as an increase in floaters -- even if the Amsler Grid looks OK -- call your doctor right away.

# DEMENTIA- AIDS Dementia Complex (ADC)

The AIDS Dementia Complex is the most common neurologic complication of AIDS, affecting about 50% of all AIDS patients. ADC is thought to be caused by HIV infection of nerve cells and resulting changes in cell function. The words "dementia complex" are used to describe the many changes in thinking and muscle function. Early signs of ADC include memory loss, difficulty in walking, and weakness. ADC is usually progressive (steadily worsens over time). The diagnosis of ADC can be made only after brain scans (CT or MRI) and a spinal tap have been done to rule out other infections. AZT has been shown in studies to improve the symptoms of ADC, however, very high doses are required. For most patients, the only treatments attempted are drugs to control severe symptoms (such as hallucinations).

# HIV Effects on the Brain - Strategies for Coping [2]

### MEMORY PROBLEMS

1. Use a daily pocket calendar.
2. Place Post-It notes in places you are sure to see.
3. Make daily and weekly lists of appointments, errands, and tasks.
4. Use alarm clock to remember when to take your pills.
5. Maintain a pill-taking log and keep next to your pill bottles.
6. Keep a log or diary for complex projects.
8. Get a noise-activated key chain.
9. Ask friends to remind you of important appointments and tasks.

### SLOWED SPEECH

1. Allow plenty of time for conversations.
2. Don't hurry; it is okay to take your time.

### PROBLEMS WITH VISION AND DEPTH PERCEPTION

1. Limit driving to a minimum.
2. Don't drive if you can't drive safely.
3. Plan your routes in advance. Allow plenty of time and take a friend along when you can.

### FEELING ISOLATED AND SAD

1. Plan events that don't have anything to do with HIV/AIDS.
2. Rekindle your sense of humor. Focus on funny TV., audio tapes, books.
3. Push yourself to get out of the house.
4. Call a psychologist or other professional if you feel overwhelmed.

### TROUBLE WITH CONCENTRATING

1. Limit confusion. Do one thing at a time.
2. Talk with people one at a time.
3. Break large jobs into smaller steps.
4. Don't drive in heavy traffic or when under stress.

### PROBLEMS WITH COMPLEX TASKS

1. Try to refuse new or unfamiliar job responsibilities.
2. Avoid tasks that have to be done fast.
3. Stick to simple daily activities, such as one-dish meals.
4. It is fine to set limits and say no.

# GINGIVITIS/PERIODONTITIS

Painful bleeding gums, bad breath, loose teeth and jaw pain may signal an infection of the gums called gingivitis. PERIODONTITIS is a deeper infection involving the teeth and bones. Both diseases are common in he general population but may be more severe in those with AIDS. Since many different diseases can affect the gums; herpes, CMV, and Kaposi's Sarcoma must be ruled out. Mild gum inflammation is treated with peridex or betadine oral rinse and an antibiotic.

Brushing and flossing after meals can help to prevent gingivitis. Get your teeth cleaned every three months.

# HERPES SIMPLEX

Herpes simplex virus causes a skin eruption usually starting as bumps (vesicles) then becoming flattened (ulcers). Herpes is transmitted by skin to skin contact, including sexual contact and kissing. In those without HIV infection, herpes is frequently recurrent. In those with HIV, the herpes may recur more frequently, be more severe, and take longer to heal. Herpes outbreaks are usually very painful. The lesions (sores) appear on the lip (fever blister) or the penis, labia, rectum and external genitals. When herpes is treated, a culture is usually done and acyclovir is prescribed based on the characteristic appearance. Acyclovir is well tolerated with minimal side effects and is taken until the lesions heal. If the herpes recur frequently, acyclovir may be taken daily to prevent outbreaks.

In addition, Famciclovir in 125 mg., 250 mg. and 500 mg. doses has been effective in treatment of herpes simplex.

# IDIOPATHIC THROMBOCYTOPENIC PURPURA (ITP)

ITP is a blood disorder that occurs when a patient's platelet count drops. Since the platelets function to clot the blood, bleeding may occur. Low platelet count may result from destruction of platelets or from a reduced production of new platelets. Both of these reasons may contribute to HIV associated ITP, but the exact reason for decrease in platelets is unknown.

No symptoms are noticed until the platelet count drops significantly to about 15,000-20,000 (normal is 150,000-400,000). Gum bleeding, blood in the stool, nose bleeds, and easy bruising are often seen when the platelet count drops.

A bone marrow biopsy is needed for diagnosis. In ITP, the bone marrow has numerous platelet producing cells (which indicates that the low platelet count is due to destruction of platelets in the blood).

## TREATMENT OPTIONS:

1 High dose AZT
2. Prednisone
3. Splenectomy (platelets often pool in the spleen)
4. Vincristine
5. Danazol
6. Immunoglobulin

ITP does not have to be treated if there is no history of bleeding and platelets remain above 20,000.

# KAPOSI'S SARCOMA (KS)

Kaposi's sarcoma is a type of cancer which involves the skin, lymphatic system, lungs, and gastrointestinal tract. KS was originally described in older men in the Mediterranean area. In these older men, the tumors were usually not aggressive. The type of KS found in AIDS is identical to the original KS when viewed under a microscope, but AIDS associated KS is much more aggressive. Most (but not all) cases of KS are found in men with a history of same-sex partners. The cause of KS in AIDS is believed to be a member of the herpes virus family, called Human Herpes virus 8. Proteins released during HIV infection are also thought to promote growth of KS tumors.

Ninety-five percent of all KS presents as a dark lesion on the skin. The lesions may also be seen in the oral cavity. The KS may also be found in the stomach, intestines and lungs. If KS involves the lymphatic system, swelling may occur in the face, penis, and legs. KS frequently appears when the CD4+ T cells are high (200-500). A biopsy (removing a piece of the tumor) is required for definite diagnosis.

Recently, two important new therapies have been approved for the treatment of Kaposi's Sarcoma. These drugs are liposomal versions of the free-form cancer drugs doxorubicin and daunorubicin. This means that the free form drug is encapsulated in microscopic lipid spheres (globules of fat) which are used to carry the drug in the bloodstream without releasing the drug. The drug is only released when the liposomes leave the bloodstream and lodge in the body tissues. This is most likely to happen within KS lesions, because the lesions are made up of a mass of abnormally growing blood vessels that are very 'leaky'. Thus, the chemotherapy is targeted to the lesions wherever they are in the body, with less of the drug affecting non-cancerous areas and causing fewer side effects. Liposomal doxorubicin is called Doxil and liposomal daunorubicin is called DaunoXome. Both drugs are closely related, and have shown KS response rates significantly better, or at least comparable to other standard treatments. These response rates are significantly higher than response rates with older regimens. In addition, toxicities with liposome-encapsulated doxorubicin and daunorubicin reveal lower rates of vomiting, mouth inflammation and hair loss than non-liposomal formulations. There has been no comparative trial yet between these two drugs, so we don't know which is better.

**Doxil:**

Is administered intravenously at 20 mg./m$^2$ (of body surface area) over 30 minutes, once every three weeks, for as long as the participant responds and tolerates the therapy. Those receiving Doxil after Doxorubicin plus Bleomycin and Vincristine combination therapy (ABV) failed have received benefit for a median of six months, or about eight cycles.

**DaunoXome:**

Also administered intravenously, DaunoXome may lead to a slightly higher incidence of neutropenia, than standard chemotherapy (see below). Neutropenia is a drop ion the absolute neutrophil count to below 1000, which can make a person with AIDS especially susceptible to bacterial infection. However, the incidence of alopecia (hair loss), fatigue and neuropathy may be significantly lower for DaunoXome.

# Other Therapies for KS [3]

### SYSTEMIC THERAPY

Systemic therapy such as Doxil or DaunoXome should be considered when painful intra-oral lesions, infiltrative disease resulting in lymphedema, painful or bulky lesions at any site, pulmonary KS (KS in the lungs) and rapidly progressive disease is observed. Other systemic therapies include Vincristine and Vinblastine; Etoposide (VP-16); non-liposomal Doxorubicin (Adriamycin); Doxorubicin plus Bleomycin and Vincristine combination therapy (also known as ABV and is more effective than Doxorubicin therapy alone); Bleomycin and Vincristine double therapy without Doxorubicin - when pre-existing low white cell count exists; alpha interferon alone or with anti-HIV therapy, and photodynamic therapy.

### LOCAL THERAPY

Local therapy may be considered when only a single or a few locally symptomatic lesions are present. It should be remembered, however, that KS is a systemic disease, and that new lesions are likely to appear in the future. At that time the decision to choose between local and systemic therapy may have to be reconsidered. Local therapeutic options include radiotherapy, intralesional chemotherapy, laser surgery and cryotherapy.

### POTENTIAL THERAPEUTIC/PREVENTATIVE APPROACHES

It is clear that cytokines and other growth factors play a role in the development and spread of KS. The list of these factors is quite long. Inhibitors of any of these factors may hold potential as treatments for KS. Some therapies currently under study for the treatment of KS include:

Angiogenesis (new blood vessel formation) inhibitors, IL-12, TNP-470, Thrombospondin, ApoE, Il-4, thalidomide, and antisense compound, retinoids, ATRA, TEC-11, SCHAL-1 (a cream containing clotrimazole), the pregnancy hormone human chorionic gonadotropin (HCG) and Taxol.

If KS is indeed caused by a herpes virus, there is a possibility that an antiviral drug may have a therapeutic effect. Foscarnet may be the available treatment with the greatest potential as it has activity against all known herpes viruses. A retrospective analysis of 20,228 patients with HIV/AIDS found that patients who were treated with foscarnet for any reason were 70 percent less likely to develop KS than people who did not receive foscarnet. Ganciclovir and acyclovir had not effect, but foscarnet has a different mechanism of action than these drugs.

# LYMPHOMA [4]

Lymphoma is a type of cancer which usually presents in the lymph nodes of non-HIV infected individuals. In AIDS, lymphoma may show up in the brain alone, in lymph nodes, or disseminated (spread throughout the body). Lymphoma involves the uncontrolled growth of dysfunctional lymphocytes (a type of white blood cell). There are two types of lymphoma, Hodgkin's disease and Non-Hodgkin's lymphoma (NHL). NHL is the one that typically affects people with HIV. It involves the uncontrolled growth of abnormal B-cells (lymphocytes responsible for antibody production). Studies have shown that the chances of developing lymphoma increase as people with HIV and AIDS live longer.

Exactly what causes NHL is not completely known. Most researchers agree that it may be a combination of factors such as Epstein-Barr (EBV) infection, gene mutations, and cytokine dysregulation (IL-6, IL-10, Il-4, IL-1, and TNF) coupled with immunosuppression. A definitive diagnosis of lymphoma can only be done through a biopsy of the involved tissue. If lymphoma is found, it is graded based on how rapid the cancerous cells are growing, and will be designated wither high, intermediate, or low grade. The lymphoma is also staged (I through IV) based on the extent of tissue involvement. Staging requires one or more of the following procedures; x-rays, whole body gallium scanning, CAT scan, MRI scan, bone marrow biopsy, and spinal tap. Stage I indicates very limited involvement at only one site while stage IV indicate very extensive involvement in multiple sites.

Lymphoma is one of the few cancers that can actually be cured! However, whether a person with HIV will survive lymphoma depends upon a number of things. Low CD4 cells (less than 100), central nervous system involvement, previous opportunistic infections and stage IV disease are all associated with poor survival rates. People with higher CD4 counts (greater than 100), no extranodal disease and no previous opportunistic infections are more likely to have a greater survival rate and potentially cured of lymphoma. Another factor will obviously be how well a patient responds to and tolerates treatment.

Confusion, memory loss, weakness, difficulty speaking, headaches or seizures may signal a lymphoma of the central nervous system (CNS). Diagnosis can be made by a brain biopsy. CNS lymphoma and toxoplasma lesions appear similar on brain scans. When a lesion is seen on a brain scan, treatment for toxoplasmosis is begun. If the lesion does not get smaller after treatment for toxoplasmosis, a brain biopsy may be done to detect lymphoma. CNS lymphoma is treated by radiation which shrinks the tumor, greatly improving quality of life, but it cannot provide a cure.

Lymphoma of the body often shows up as swollen lymph glands. Fever, weight loss, and night sweats may accompany the swollen glands. Very large lymph glands or newly enlarged lymph glands are biopsied to see if lymphoma is present. Often in AIDS the lymphoma has spread throughout the body by the time it is discovered. Depending on the overall health of the patient and the extent of the disease, chemotherapy may be an option.

## TREATMENT:

There are primarily two standard treatments for AIDS-related NHL:

**1. CHOP** (Cyclophosphamide, Hydroxydaunomycin, Oncovin, and Prednisone) and

**2. mBACOD** (Methotrexate [low dose], Bleomycin, Adriamycin, Cyclophosphamide, Oncovin and Dexamethasone).

One study of non-AIDS related NHL comparing four different chemotherapy regimens of which CHOP and mBACOD were included, showed that CHOP was the best treatment based on the fact that it was less toxic. Unfortunately, there was no significant difference among the four different treatments regarding response rates.

Response rates to treatment are difficult to clearly define. While there are reports of response of 50% and higher for some treatment regimens, the length of survival can still range from several weeks to years. One of the most recent lymphoma studies (ACTG 142) reported a median survival time of approximately eight months. The problem lies in the fact that while the lymphoma may be completely cleared for a period of time, the typical person with AIDS-related NHL is severely immunosuppressed, may experience other opportunistic infections or even experience NHL relapse.

One complication of NHL relapse is that the lymphoma may come back as primary central nervous system (CNS) lymphoma. For this reason, researchers believe that intrathecal prophylaxis may be beneficial. This is a procedure in which the chemotherapy is injected directly into the spinal canal to prevent the lymphoma from spreading there. Some researchers believe this should be done on all patients with AIDS-related NHL, others believe that intrathecal prophylaxis should only be used on patients with particular types of disease such as bone marrow and epidural (the outermost covering of the brain and spinal cord) involvement, and sinus disease.

## SIDE EFFECTS:

The use of these chemotherapies can also result in numerous side effects and toxicities. Side effects can include nausea, vomiting, fatigue, diarrhea, swollen/sensitive gums, mouth sores, hair loss, and peripheral neuropathy (numbness, heat, or tingling sensation in the hands and/or feet. Drugs such as Zofran can be used to control the nausea and vomiting. These chemotherapies can also have a significant impact on decreasing a person's white blood cell count which increases the risk of bacterial infections. Colony stimulating factors such as G-CSF (Neupogen) or GM-CSF (leukine) can be used to increase the white blood cell production, reducing the risk of infections.

## EMERGING TREATMENTS:

There is research on-going for treatments for NHL to improve upon what we currently have. Some compounds currently being investigated include:

**Anti-B4 blocked ricin in combination with CHOP.** The anti-B4 is a monoclonal antibody which will attach specifically to B-cells. Ricin is a toxin. The theory is that these antibodies will attach to the lymphoma cells specifically and the ricin will kill these cells. Another study is being done using only anti-B4 blocked ricin inpatients who have NHL relapse.

**MGBG** (Methyl-gloyoxal-bis guanlhydrazone) was abandoned several years ago due to toxicity, but is being studied again, with lower doses, in patients with NHL relapse or refractory disease.

**Autologous Stem Cell Transplants in Combination with High Dose Chemotherapy.** This is a process in which patients with NHL relapse are given G-CSF to increase the production of CD34+ cells, which are then removed and stored. The patient is then given high-dose chemotherapy and radiation to treat the lymphoma, and then given back their CD34+ cells. Ideally, the chemotherapy will be effective without the opportunity to destroy a patient's white blood cells.

# MYCOBACTERIUM AVIUM COMPLEX (MAC or MAI)

Mycobacterium Avium Complex (MAC) refers to a group of related organisms belonging to a family called **mycobacteria**. Mycobacteria also cause tuberculosis and leprosy. The organisms causing MAC are found in many locations (soil, water, animals, and dairy products) and is, therefore, difficult to avoid. Before AIDS, MAC was seen only rarely. Current estimates are that up to 40% of people with AIDS will develop symptomatic infection with MAC. MAC spreads from the gastrointestinal tract to eventually infect the blood, liver, spleen, and bone marrow. Symptoms of disseminated infection include fever, night sweats, diarrhea, abdominal pain, weight loss, liver failure and anemia. MAC is usually diagnosed by blood, stools or sputum culture although organ biopsy may be needed. Disseminated disease is difficult to treat. At least three and usually four drugs are required to treat MAC because the organism readily develops resistance. The drugs cannot cure the disease completely, merely relieving symptoms and prolonging life. Given the resistance to treatment, prevention of MAC is a major research goal.

MAC Prophylaxis is recommended when the CD4 count is less than 75 or 5%. Due to concerns about drug resistance, it is crucial to be tested for Tb **prior** to beginning prophylaxis for MAC. Following are three current options for MAC prophylaxis:

### 1. RIFABUTIN:

Rifabutin is FDA approved for the prevention of MAC at 300 mg. per day. Disseminated MAC disease should be ruled out (by negative blood culture) before prophylaxis with Rifabutin is begun. Rifabutin is similar to Rifampin, a drug used to treat tuberculosis (TB). The possibility that TB may develop resistance to Rifampin has not been thoroughly addressed. Drug resistant TB is developing in many parts of the country and is difficult to treat.

### 2. CLARITHROMYCIN:

Clarithromycin (Biaxin) is FDA approved for MAC prophylaxis at 500 mg. two times a day. While studies indicate this drug is effective in MAC prevention, there is considerable concern about MAC becoming resistant to Clarithromycin, which is the most potent.

### 3. AZITHROMYCIN:

Azithromycin 1200 mg. weekly. The combination of azithromycin and rifabutin may be more effective than either alone and may prevent resistance to the drugs. This is currently under study.

# Tips on Preventing MAC/MAI [5]

Mycobacterium avium complex (MAC) causes disseminated disease in up to 40% of patients with advanced HIV in the United States. MAC is the most common AIDS-related bacterial infection, affecting 50% of PWAs within two years of AIDS diagnosis.

The bacteria that causes MAC is found almost everywhere in the environment: in water, soil, animals, insects, dairy products and poultry, etc., and is difficult to avoid. The organism is in the tuberculosis family and can spread from the mouth or gastrointestinal tract to the lungs, liver, lymph nodes, spleen, bone marrow, intestines and blood. MAC can cause a wide range of chronic debilitating symptoms including persistent fever, night sweats, weight loss, fatigue, liver dysfunction, chronic diarrhea, abdominal pain and severe anemia.

In addition to the medications listed on the previous page, there are some things you can do to help prevent MAC. The late Dr. Larry Waites, a well known and respected HIV physician, **cautioned against drinking tap water, reminded us to use gloves when working in the garden, and quoted the now widely known saying "cook it , peel it, bleach it, or forget it" when preparing and eating fruits and vegetables.** Following the above recommendations plus innovative and preventative treatment strategies helped Dr. Waites to nearly eliminate MAC from his practice.

# DRUGS USED TO TREAT MAC/MAI AND THE KNOWN SIDE EFFECTS

1. **Rifampin:** Urine and sweat will become orange; can be toxic to the liver.

2. **Ethambutol:** Visual changes.

3. **Clarithromycin/Azithromycin:** Nausea.

4. **Clofazimine:** Skin discoloration.

5. **Ciprofloxacin:** Nausea, diarrhea.

6. **Amikacin (IV):** Given only for severe MAC; unresponsive to oral therapy; may cause liver and kidney damage.

MAC usually does not cause symptoms until the CD4+ cells are below 75.

# MAC Treatment News from the 11th International Conference on AIDS

Important data on clarithromycin dosing for MAC therapy were presented by David Cohn, et al. In a randomized trial, patients with disseminated MAC were randomized to one of two doses of clarithromycin (500 mg. twice daily or 1000 mg. twice daily) with ethambutol plus either rifabutin or clofazimine. An interim review in February 1996 identified increased mortality in the 1000 mg. group which could not be attributed to disease severity. Therefore ALL patients were switched to 500 mg. twice daily.

After the Vancouver meeting, the NIH issued an alert to clinicians warning against the use of high-dose clarithromycin for therapy. This is particularly important since the use of macrolides as MAC prophylaxis is increasing, and some clinicians might be tempted to treat prophylactic breakthroughs with high doses. This study and data from two previous studies indicate 500 mg. twice a day is the safest therapeutic dose for MAC.

Another alert to clinicians followed shortly, warning against the use of clofazimine in the treatment of MAC. This recommendation was made in light of a study by Abbott Pharmaceuticals comparing a three-drug combination of clarithromycin, ethambutol, and clofazimine. There was an increase in mortality that could not be attributed to disease severity in the study arm containing clofazimine. **Therefore, until new data is available, the combination of clarithromycin (500 mg. twice a day) and ethambutol (with or without rifabutin) should be used as initial treatment for MAC.**

# PNEUMOCYSTIS CARINII PNEUMONIA (PCP)

Pneumocystis carinii is a fungus which is found commonly in the environment. The organism is inhaled into the lungs and may remain there in small numbers in healthy people. When the immune system begins to fail, the organism causes inflammation in the lungs (pneumonia). In AIDS, PCP is the most common opportunistic infection and remains a common cause of death. The development of lung inflammation occurs over weeks to months causing progressive shortness of breath and a dry cough. It is often difficult to diagnose because chest x-rays may appear normal and typical signs of pneumonia (such as fever) may be absent. If treated early, the pneumonia is easily contained. While prophylaxis is controversial for other infections, research easily indicates that PCP can be prevented. The same medications used to treat PCP can be used to prevent the inflammation from occurring.

## THE MAIN PROPHYLACTIC REGIMENS TO PREVENT PCP

**1. Trimethoprim/Sulfamethoxazole (Bactrim or Septra):**

This drug is a combination of two antibiotics. Bactrim/Septra is currently recommended as the first choice for PCP prophylaxis and can prevent up to 97% of PCP cases. The drug is taken either once daily or three times a week. I recommend a daily dose (if tolerated) because Bactrim/Septra may also prevent toxoplasmosis. Up to 50% of HIV infected individuals are allergic to the sulfa component of this drug. If a rash, fever, or itching appears after taking the drug, stop it immediately and then call your doctor. Nausea, granulocytopenia (lowering of a certain type of white blood cell) and kidney dysfunction can also occur as side effects. Monitoring of blood work periodically is necessary to catch signs of these problems early especially if you are taking AZT which can also lower granulocytes.

*Note:* AIDS Survival Project's Treatment Library has a protocol for desensitization to Bactrim/Septra that may help if you are allergic. If you are interested, pick up a copy of the protocol and discuss it with your doctor.

**2. Dapsone:**

This drug is currently the second choice for PCP prophylaxis. Dapsone is usually given as a dose of 50 mg. a day or 100 mg. every other day. Some who are allergic to sulfa will also be allergic to the sulfa component of Dapsone. The number of people allergic to Dapsone is much lower than that for Bactrim/Septra. A dangerous side effect called hemolysis (breaking open of red blood cells) can occur if a patient lacks an enzyme called G6PD. A G6PD level should be checked before beginning Dapsone. Nausea, liver dysfunction and a rare condition called methemoglobinemia can occur.

**3. Aerosolized Pentamidine:**

While still relatively effective, this once frequently used therapy is now a last choice. Bactrim/Septra and Dapsone given orally are more effective and can prevent PCP from spreading beyond the lungs. Pentamidine treatments can also cause chest x-rays to lack "typical" features of PCP. Another benefit of the oral drugs is the prevention of toxoplasmosis (a brain infection dealt with later). Only those unable to tolerate oral medications now receive aerosolized pentamidine. Side effects are usually minor and include a cough or wheezing which can be prevented by taking bronchodilators before the pentamidine.

**Prophylaxis for PCP should start when CD4 + T cells are around 200 (or 20%). Those with a history of PCP, an AIDS defining opportunistic infection, unexplained wasting, fever, or thrush should also consider PCP prophylaxis.**

# TREATMENT OF PCP

PCP is usually treated with Bactrim. If a patient is allergic to sulfa or has another reason not to use Bactrim, then intravenous pentamidine is the second choice. If the pneumonia is very severe causing hypoxia (low blood oxygen), then steroids are added to the antibiotic in order to help reduce the inflammation in the lungs. Other possible treatments for PCP, if the case is mild, include oral Bactrim/Septra, Dapsone and Trimethoprim, Clindamycin and Primaquine, Atovaquone (Mepron). After treatment for PCP, it is essential to begin or continue prophylaxis. If you developed PCP despite being on prophylaxis, a second drug may be added.

# SHINGLES

Viruses in the herpes family usually remain in the body for a lifetime causing recurrent outbreaks. In childhood, most individuals are infected by the Varicella-Zoster virus which causes chickenpox. Once the chickenpox heal, the virus remains in the body- favoring the nerve cells. The virus often remains in the body without ever being noticed. Whenever the immune system is unhealthy (severe stress, diabetes, HIV infection, etc.), the virus can travel down the nerve cells to infect the skin. This infection is called shingles and usually infects one area of the skin (called a dermatome). In HIV infected individuals, the Shingles can infect the entire skin and even internal organs.

Shingles usually begins as painful blisters which may then open into ulcers. The shingles will usually heal by themselves in 2-3 weeks. Treatment with Acyclovir can shorten the period of skin infection and decrease the amount of pain. The Acyclovir will not eliminate the virus- it merely forces the virus back into the body faster. The shingles may reappear at a later time.

Severe pain is treated with various medications. Once the lesions clear, pain may persist in what is known as post-herpetic neuralgia. The neuralgia can be treated by a cream called Zostrix.

If the shingles involves the eye area, hospitalization may be required.

It is very important to keep the lesions clean and dry so they do not become infected by bacteria on the skin.

# SINUSITIS

The bones of your face contain small cavities called sinuses. The sinuses are lined by a tissue that may become inflamed and cause sinusitis. Frequently, bacteria enter the sinuses and cause an infection. This often occurs after a cold. Sinus complications of HIV infection range from minor congestion to persistent sinus drainage (down the nose or throat) to bacteria infections. Signs of bacterial infections include pain, headache, fever, drainage of yellow to green discharge and postnasal drip. Infections are treated with one of numerous antibiotics. Symptoms of sinus congestion (but not infection) respond to multiple kinds of decongestion.

# SKIN ABNORMALITIES

HIV infected individuals are at high risk for many skin (dermatologic) abnormalities.

### 1. SKIN INFECTIONS

The bacteria staphylococcus aureus may cause numerous skin infections: folliculitis (hair follicle), cellulitis (infection of the outer layers of skin), and abscesses ("boils"). Depending on the extent of infection, either oral or intravenous (IV), antibiotics are required to heal the lesions.

### 2. SEBORRHEA

Flakiness of the skin on the forehead, above the nose, on the scalp, the groin. Selenium or hydrocortisone will heal the lesions but seborrhea usually recurs.

### 3. HERPES SIMPLEX

Please see the information on Herpes Simplex earlier in this section.

### 4. SHINGLES

Please see the information on Shingles earlier in this section.

### 5. KAPOSI'S SARCOMA

Please see the information on Kaposi's Sarcoma earlier in this section.

### 6. MOLLUSCUM CONTAGIOSUM

This is a benign infection of the skin caused by a pox virus. The lesions are small, raised and may be numerous. The virus can be transmitted by touch and sexual contact. The lesions are not harmful but may be removed by liquid nitrogen or Condylox, a topical paste.

### 7. SYPHILIS

A sore called a chancre can occur at the site of infection by sexual contact. In the later stages a rash may be seen on the skin, palms of the hands, and soles of the feet.

### 8. FUNGAL INFECTIONS

Please see the information on fungal infections (Candidiasis, Cryptococcus, Tinea) elsewhere in this section.

# QUESTIONS TO ASK YOUR HEALTH CARE PROVIDER ABOUT TB [6]

Because HIV weakens the body's ability to resist infections, you are at special risk for infection with the germ that causes tuberculosis (TB). Even if you become infected with this germ, proper treatment can keep it from turning into active TB. Be sure to ask your doctor, nurse, or other health care provider:

- How often should I be tested for TB infection? What kinds of tests are needed?
- How can I avoid becoming infected with TB?
- If I get TB, how can I avoid infecting others?
- Tell your health care provider if you think you have been exposed to someone with TB.

If you become infected with the bacteria that causes TB, your doctor may give you the medicine, isoniazid (INH), which you will need to take once a day, every day, for a full year, even if you feel fine. Your doctor may also recommend that you take pyridoxine, a form of vitamin B6, each day to help reduce side effects from isoniazid. Be sure to tell your doctor about any side effects you may have from the medicine, such as nausea, vomiting, loss of appetite, tiredness or weakness, skin rashes, or fever.

Instructions for taking medication for TB infection can be confusing. Work closely with your health care provider to be sure you complete your treatment.

# TUBERCULOSIS (TB)

TB is an infection caused by Mycobacterium tuberculosis which is spread from person to person by respiratory secretions (coughing, talking etc.). The organism is breathed into the lungs, multiplies there and eventually travels to lymph modes where it may spread throughout the body via the blood. In healthy individuals, the immune system is able to inactivate the TB although it still remains in the body. When the immune system fails (AIDS, old age, malnutrition) the TB may reactivate to cause new symptoms.

Patients with HIV can develop active TB from two sources: 1) Reactivation of TB already in the body or 2) New exposure to the TB organism (breathed into the lungs). TB may cause a lung infection but 50 - 70% of patients with HIV have "extrapulmonary" TB. (Extrapulmonary TB means TB infection outside of the lungs). TB can infect any part of the body including the brain, joints, bone marrow and blood. The most common symptoms of TB are: fever, night sweats, weight loss, loss of appetite and cough.

TB is usually easy to diagnose since the organisms can be seen using special stains in the lab. TB and MAC appear similar on these stains so definite diagnosis may take up to six weeks (for cultures to grow).

All HIV infected individuals should have a skin test known as a PPD. This test is used to see if there is a history of TB infection. In the test, a drop of PPD is put under the skin of one forearm while controls are placed on the other arm. (Once the immune system is exposed to an organism, special cells develop which will attack that organism if it ever appears again in the body. The skin test uses small amounts of inactive TB derivatives in the PPD arm and small amounts of mumps or candida in the other arm. All patients should react to the control since everyone has been exposed to these organisms. The problem with the test in HIV infected individuals is that T cells are required to cause a positive skin reaction (swelling). So if your T cells are low you may not respond to the PPD or to the controls. This is called anergy). There are three possible results of the TB skin test. If the PPD arm is positive and the control arm is positive then you have been exposed to TB at some point in your life. If the control is positive and the PPD is negative, you probably have not been exposed to TB. If both arms are negative, you are anergic, and no judgements may be made about your exposure to TB. A chest x-ray should be done yearly in all anergic individuals.

All individuals with a positive TB skin test should be evaluated for active disease. If your doctor finds no signs of active infection, a medication called Isoniazid should be taken for one year in order to prevent the TB in your body from becoming active. Liver dysfunction may occur when taking Isoniazid. A vitamin called Pyridoxine (B6) should be taken along with the Isoniazid in order to decrease the chance of peripheral neuropathy which is another possible side effect of the drug.

Regardless of the site of infection, active TB is treated with the same drugs. Since TB readily develops resistance to fewer drugs, at least three medications are required for treatment. Common TB drugs include Isoniazid, Rifampin, Pyrazinamide, and Ethambutol.

TB is very contagious. If you are coughing you should wear a mask-- especially at the doctor's office. If you are diagnosed with TB in the lungs, your family and significant others should be given a TB skin test and chest x-ray.

# TB and HIV [7]

### WHAT IS THE CONNECTION?

HIV infection weakens the body's immune system and makes it more likely for a person with latent TB infection to develop active TB. HIV infection is one of the strongest known risk factors associated with the progression from TB infection to active TB. HIV-related TB is unique in that it is one of the few clinical manifestations of HIV infection that is communicable, treatable and preventable. All TB patients should be tested for antibodies to HIV.

### KEY POINTS TO REMEMBER:

**Diagnosis (for HIV-positive persons)**

- All persons who are HIV positive should have a Mantoux tuberculin skin test.
- All persons with or at risk for HIV infection (especially IVDUs) should be given a TB skin test.
- Persons with both HIV and TB infections may have falsely negative skin test reactions because of immunosuppression.
- Health care providers of HIV-infected persons must be aware that TB may present in unusual ways in this group (for example, with TB in the lymph nodes or in the lower portion of the lung).

**Treatment (for HIV-positive persons)**

- Persons with both active TB and HIV infection respond well to TB treatment. However, treatment should be given for a longer period of time than the standard regimens used for persons with TB who are HIV negative.
- Treatment should last for a minimum of 9 months and for at least 6 months beyond the date when cultures become negative.
- If either isoniazid (INH) or rifampin (RIF) is not, or cannot be, included in the regimen, therapy should last for at least 18 months and for a minimum of 12 months following culture conversion.
- Preventive therapy for HIV-infected persons should also be given for a longer period of time than the regimens used for persons not infected with HIV (INH for 12 months instead of 6 months).

**Infection control**

- All persons with HIV infection and undiagnosed pulmonary disease should be suspected of having TB. Appropriate precautions to prevent airborne transmission should be taken until TB is diagnosed and treated or ruled out.
- These precautions are most important during and immediately after procedures that may induce coughing, such as bronchoscopy, sputum collection, aerosol induction of sputum and administration of aerosolized medications such as pentamidine.
- Health care workers who have regular contact with persons with TB or HIV infection should participate in an ongoing TB screening program.

*Note on MDR-TB:* There is another form of TB called Multi-drug Resistant Tuberculosis (MDR-TB). MDR-TB is TB that does not respond to at least two of the approved drugs for treatment. The strains of MDR-TB are identified by how many drugs they are resistant to. While this is a very serious illness, there have been many successes in treating different strains of MDR-TB. There is nothing to suggest that MDR-TB is any more infectious than any other form of TB.

If you have any questions, please call the AIDS Survival Project Treatment Resource Specialist at (404) 874-7926.

# TINEA

This fungus (and other skin fungi) causes "athlete's foot", "jock itch", and nail infections. The skin infections usually respond to ointments but if severe, may require oral drugs. Nail infections are almost impossible to treat. However, Itraconazole (Sporanox) has shown favorable response.

# TOXOPLASMOSIS

Toxoplasmosis is an infection caused by a parasite called **toxoplasma gondii.** Humans acquire toxoplasma by eating undercooked pork or lamb or through contact with cat feces. In healthy people, infection with toxoplasma is usually mild and is usually not even noticed. The immune system inactivates the toxoplasma but it remains in muscle and brain tissue. When the immune system fails (as in AIDS), the toxoplasma may reactivate and cause a brain infection. Signs of toxoplasma brain infection include headaches, changes in thinking, seizures, weakness and change in walking.

Toxoplasma does not usually reactivate until the CD4+ cells are below 100. Most (but not all) patients who develop the brain infection will test positive for antibodies to toxoplasma. When any of the above signs of toxoplasmosis are found, a brain scan (preferably an MRI) is performed to look for the infection. Treatment is usually begun based on the results of the MRI. If no response is noted after treatment, a brain biopsy may be needed to see if the lesion is really toxo (or something else). Treatment of toxoplasmosis is usually successful if it is caught early enough.

**Treatment always includes pyrimethamine** which can slow down the production of blood cells. For this reason, pyrimethamine is always given with Folinic acid to help counteract this side effect. Sulfadiazine is recommended as the first choice for the second drug. If unable to tolerate sulfadiazine, a patient may be given clindamycin. Reduced doses of the drugs used for treatment are required for life to prevent the toxo from reactivating again.

## PROPHYLAXIS TO PREVENT TOXOPLASMOSIS

Studies have shown that Bactrim or Septra when given to prevent PCP also reduced the chances of reactivation of toxoplasma. The same dose of Bactrim or Septra used as PCP prophylaxis should suffice for toxo prevention. For those with CD4+ T cells below 100 and a positive blood test for toxoplasma antibodies, many physicians suggest a daily dose of Bactrim or Septra (as opposed to a Mon/Wed/Fri regimen). Some studies have indicated that dapsone may also help to prevent toxoplasma reactivation although the conclusions are less clear. Pyrimethamine used alone as prophylaxis is being studied. Given the toxicity of pyrimethamine, it is probably best to wait for definite information about its safety and effectiveness.

# Project Inform Guide to the Management of Opportunistic Infections

6

| Opportunistic Infection | Symptoms of Active Infection | Diagnostic Procedures | Treatments (Tx) for Active Infection |
|---|---|---|---|
| **Mycobacterium Avium Complex (MAC or MAI)**<br>a bacterial infection | **General:** persistent fever, night sweats, fatigue, weight loss, chronic diarrhea, anemia, thrombocytopenia (low platelets), abdominal pain, weakness, dizziness, nausea. Also, enlarged lymph glands (frequently on one side), enlarged liver and spleen, and soft tissue masses (especially in the thighs). May be **organ-specific** or **disseminated.** | Can be difficult to diagnose. Lab Tests; blood, sputum and stool cultures, organ tissue biopsy and culture. Often treated prior to definitive diagnosis if smear positive for Acid Fast Bacilli (AFB). Elevated alkaline phosphatase may indicate MAC infection. | **Clarithromycin** 500 mg. BID or **Azithromycin** (EA, ANH, CT) 500-600mg./ day (Monitor for resistance) in combo. w/ at least one of the following: **ethambutol, clofazimine, ciprofloxacin, rifabutin,** (monitor **clarith.** blood levels). **Amikacin** (IV), **Sparfloxacin** (CT) (various combo's in CT) If failing **Clarithromycin,** try **liposomal gentamycin** (CT, EA). |
| **Tuberculosis (TB)**<br>a bacterial infection | Similar to MAC. May be pulmonary (lungs), or extrapulmonary (other organs) especially meningitis. Cough, weight loss, night sweats, fatigue, fever, swollen lymph nodes, or organ specific symptoms. Can occur at any CD4 range. | PPD skin test with greater than 5mm reaction. Chest X-ray. Sputum smear, culture and sensitivity, blood, bone marrow, or liver cultures. See April '92 ***PI Perspective.*** | Treat with at least 3 oral drugs: **Isoniazid (INH), pyrazinamide (PZA)** and **rifampin**; when resistance suspected add **ethambutol;** if treatment failure or intolerant **streptomycin** (EA) or **L-ofloxacin** or **sparfloxacin.** Monitor for drug resistance. |
| **Candidiasis (Thrush)**<br>a fungal infection | **Mouth or esophagus:** white patches on gums, tongue or lining, pain and difficulty swallowing. Loss of appetite.<br>**Vagina:** itching, burning, vaginal discharge. | **Mouth and Vagina:** visual exam, smear and culture.<br>**Esophagus:** often treated presumptively, confirmed by biopsy culture. | **Fluconazole, nystatin, clotrimazole** troches or cream. **Ketoconazole, Itraconazole** . **ABLC** (CT) (CU). **Vaginal:** First try yogurt and/ or vinegar douche, garlic, then topical creams, then oral systemic drugs. |
| **Cryptococcosis (Cryptococcal Disease)**<br>a fungal infection | **Meningitis.** Most common: mild headache and intermittent fevers. Progressive malaise, nausea, fatigue, loss of appetite. Altered mental status, seizures (rare). May also cause a form of pneumonia (mimicking PCP, sometimes occurring at the same time as PCP). Disseminated infection of multiple organs, may cause skin lesions. | Testing for cryptococcal antigen (CRAG) on serum, cerebral spinal fluid (CSF), India ink stain on CSF. Chest x-ray for pneumonia. With altered mental status, seizures or other neurological problems, CT or MRI scans should be done to rule out other factors, followed by lumbar puncture (spinal tap). | **Fluconazole** (oral or IV). **Amphotericin-B** with or w/out **5-flucytosine (5-FC): (ampho-B** often used first, particularly in severe cases with **5-FC** followed by **fluconazole**). **ABLC, ABCD, liposomal ampho-B** (CT). **Itraconazole** (CT). **Dexamethasone + ampho-B** for patients with high cranial pressure. |
| **Histoplasmosis**<br>a fungal infection | Fever, weight loss, difficulty breathing, skin lesions, anemia, lymphadenopathy (swollen lymph nodes). May cause pneumonia. | May be difficult to diagnose. Blood and sputum culture, bone marrow biopsy and culture, lymph node biopsy or skin lesion biopsy. Chest x-ray. | **Itraconazole, Amphotericin-B** (IV), **fluconazole, ABLC, liposomal ampho B** (CT) (CU). |
| **Cryptosporidiosis**<br>a protozoal infection | Diarrhea with frequent watery stools, abdominal cramping, nausea, vomiting, fatigue, flatulence (gas), weight loss, loss of appetite, constipation. Dehydration and electrolyte imbalances (sodium & potassium). | Stool tests (often repeated tests are necessary), bowel biopsy, endoscopy. May be infected but asymptomatic. | No standard Tx. **Azithromycin** oral or IV (CT, CU). **Paromomycin** (humatin), **Atovaquone** (CT, CU), **bovine colostrum** (CT). **Immuno-C** (CT), **NTZ** (CT). **Octreotide** (and others for symptoms only). Nutritional therapies. |
| **Pneumocystis Carinii Pneumonia (PCP)**<br>a protozoal infection | Fever, dry nonproductive cough, difficulty in breathing, weight loss, night sweats, fatigue, elevated serum LDH (a liver enzyme). | Chest x-ray, sputum induction* gallium scan, bronchoscopy*.<br>* Requires special stain to identify organisms. | Systemic Tx preferred. **TMP/SMX** (IV or oral) same as **bactrim, septra & cotrimoxasole. Pentamidine** (IV), **Dapsone** with or without **trimethoprim** (CT) (EA). **Atovaquone** for mild to moderate PCP. **Trimetrexate** IV (IND), **Primaquine** (BC) with **clindamycin.** Corticosteroids might be added to any of the above in moderate to severe cases. |
| **Toxoplasmosis (Toxo)**<br>a protozoal infection | Encephalitis most common: altered mental state (lethargy, confusion, delusional behavior), paralysis on one side of body, seizures, severe headaches that do not respond to pain killers, fever, coma. May also cause symptoms outside CNS, notably in lungs and heart and eyes. | Baseline Toxo antibody titer (when diagnosed with HIV) to verify past exposure. Usually treated presumptively if antibody positive and MRI scan shows brain lesions; also, brain biopsy to rule out lymphoma. Can do tissue culture and CSF. Requires special stain to identify. If Toxo-negative, avoid cat feces and undercooked meat and fish. | Always treat with combination therapy.<br>**Pyrimethamine** with any of the following:<br>• **Sulfadiazine** ***or*** **Clindamycin**<br>• **Sulfadiazine & Clindamycin** (CT)<br>• **Azithromycin** (EA).<br>• **Sulfadiazine & rIFN Gamma** (CTP).<br>• **Atovaquone** (CT). Folinic acid supplement should be used. |
| **Cytomegalovirus (CMV)**<br>a viral infection | **Retinitis:** blurry vision leading to blindness.<br>**Esophagitis:** ulcerations, pain and difficulty in swallowing. **Colitis:** fever, diarrhea, abdominal pain, wasting.<br>**Pneumonia** (rare): usual pneumonia symptoms (see PCP) | Should do baseline CMV antibody titer to verify past exposure. For retinitis, an "Amsler Grid" or Teich test can be self-administered to check for early vision loss (see page 202), followed by a professional retinal exam. For other types of CMV, biopsy and endoscopy. | **Ganciclovir** (DHPG) IV, **Foscarnet** IV, Combo of **ganciclovir** and **foscarnet** (CT), **Ganciclovir** implants (intraocular) (CT). **IV cidofovir** and **intravitreal cidofovir** for retinitis (CT). **MSL-109** (monoclonal antibodies) (CT) for retinitis. **ISIS 2922** (antisense) for retinitis (CT), **lobucavir** for retinitis. |
| **Herpes Simplex, Shingles**<br>viral infections | Painful blisters, ulcers, itching on the lips **(HSV-1)**, anus and/or genitals **(HSV-2)**. Shingles on body in Herpes Zoster **(Varicella Zoster Virus or VZV)**. **VZV** is a reactivation of chicken pox and usually occurs on legs or torso. | Visual exam, tissue biopsy and culture. (HSV Esophagitis may also occur and appears similar to CMV or Candida). | **Acyclovir** (oral or IV), **valacyclovir** (oral), oral **famciclovir.** If **acyclovir**-resistant, **foscarnet** (IV) or topical **trifluridine (TFT),** topical **cidofovir** (CT), or topical **foscarnet** (CT). **Sorivudine** (CT). |

**Legend:** **EA** = Expanded Access
**CU** = Compassionate Access
**CT** = Clinical Trial
**BC** = Buyers Club
**ANH** = Approved only for non-HIV related indications
**CTP** = Clinical Trial Pending
**BID** = Twice a day

# Project Inform Guide to the Management of Opportunistic Infections

| Prophylaxis (Px) and Maintenance (Mx) Options | Possible Side Effects | Drug Interactions (and notes) |
|---|---|---|
| Risk of MAC increases when CD4 count is <75 or 5% Px: **Rifabutin** FDA approved for Px at 300 mg./day or **Clarithromycin** FDA approved for Px at 500 mg. 2x/day (resistance may be an issue). **Azithromycin** 1200 mg./week. Combination of azithromycin + rifabutin may be more effective than either drug alone. May also prevent resistance to the drugs. Mx: required after treatment for active disease. Treatment doses may be required.<br>**Note:** *TB skin test **before starting prophylaxis.*** | **Rifabutin:** rash, fever, GI distress, hemolysis, decreased WBC & platelets, uveitis, joint pain. **Ethambutol**: liver toxicities, vision changes, vomiting, diarrhea. **Clofazimine**: skin discoloration, itchy, dry skin, rash. **Ciprofloxacin**: nausea, diarrhea, vomiting. **Amikacin**: kidney, liver toxicity, hearing loss. **Clarithromycin**: nausea, reversible hearing loss. **Azithromycin**: nausea, loose stools and hearing loss. **Sparfloxacin**: photosensitivity. | Avoid alcohol with liver-toxic drugs. **Rifampin**: ***ketoconazole*** affects many drugs metabolized through liver. May affect ***Methadone*** metabolism. **Ciprofloxacin**: avoid **antacids. Cyclosporine** or **Probenecid**: monitor kidney functions. **Amikacin**: avoid **ampho-B**, diuretics, penicillins. **Clindamycin**: avoid **erythromycin. Clarithromycin**: can reduce ***AZT*** levels by one third. **Rifabutin** can reduce ***clarithromycin*** blood levels by 50%. Both **Clarithromycin & Rifabutin** may interact with ***Fluconazole & Itraconazole & Protease Inhibitors.*** ** |
| Tb risk increases with PPD skin test of >5 mm reaction, or history of positive PPD. Mx/Px: **isoniazid** 300 mg. (Take w/ Vitamin B6) for 1 year (CT). **Rifampin** 450 - 600 mg. (by weight) with **pyrazinamide** 50 mg./day (CT). | **Isoniazid**: peripheral neuropathy and liver toxicity. **Rifampin**: liver & kidney toxicities, rash, discoloration of body fluids. **Pyrazinamide**: liver toxicity, nausea, vomiting, diarrhea. **L-Ofloxacin:** GI disturbances, nausea, headache and insomnia. | Infection control important with active Tb. Yearly testing important as Tb epidemic spreads. **Isoniazid:** avoid ***antabuse, ketoconazole***, and tuna fish; monitor liver. See above for **Rifampin** and **Amikacin. Ethambutol**: avoid co-administration with *Aluminum Salts (ALOH)*. |
| Risk increases as CD4's fall < 75 or 5%. Px thought preferable to dealing with active infection by some but fluconazole resistance becoming an issue. Px: **Fluconazole** 100 - 200 mg./day. Mx: **Fluconazole** 50 - 200 mg./day. **Vaginal**: Any CD4 count, Px and Mx same as Treatment. Use topical or troches before systemic Px. | **Nystatin**: diarrhea, gastrointestinal upset with high doses. **Fluconazole**: nausea &/or headache, rare liver reactions, abdominal pain. **Itraconazole**: similar. **Ketoconazole**: can be toxic to liver (fatal), headache, drowsiness, dizziness.<br>*Monitor for resistance to these drugs.* | **Fluconazole**: avoid ***Hismanal, Seldane,* warfarin, rifampin, oral contraceptives, cimetidine (tagamet), dilantin, hydrochlorothiazide, & sulfonylureas. Itraconazole & ketoconazole**: ***Seldane, Hismanal,*** **Protease inhibitors, antacids** & ***ddI***, take 2 hrs apart. **Flu & Itra** may interact with ***clarithromycin & rifabutin.*** **Clotrimazole**: raises liver function tests. |
| Risk increases as CD4's fall < 75 or 5%. Cryptococcal antigen tests should be done regularly. If positive, follow with cultures. Px: **Fluconazole** 100 - 200 mg./day. Mx important indefinitely: **Fluconazole** 200 - 400 mg./day. **Amphotericin B** appears inferior to fluconazole as Mx. Consider **Itraconazole** 200mg./day, but this has poor penetration into CNS. | **Fluconazole**: see above. **Amphotericin B**: damage to kidneys (fluid loading may reduce this; monitor BUN and creatinine levels), anemia, chills, fever, headache, vomiting, diarrhea, cramping, low blood pressure and abnormal heartbeat. **ABLC, ABCD** and **liposomal ampho-B** are reportedly less toxic. **5-Flucytosine** (5-FC): nausea, diarrhea, vomiting, severe bone marrow suppression, liver toxicity. **Itraconazole:** see above | See above for **fluconazole. Amphotericin B**: avoid steroids, some antineoplastics; may be synergistic with ***flucytosine***, requires frequent monitoring of various blood levels; some side effects treatable. **Flucytosine** requires close monitoring of blood, kidney & liver functions. |
| Risk increases as CD4's fall < 75 or 5%. However, no Px regimens being studied. Mx: **itraconazole** 200 mg. twice a day better than **fluconazole** 600 mg./day. | See above for information about **fluconazole, itraconazole** and **amphotericin B**. | See above for information about **fluconazole, itraconazole** and **amphotericin B.** Histoplasmosis is most common in the river valleys of the Midwest, especially Kansas. |
| Risk increases as CD4's fall < 75 or 5%. However, as in Tx, there is no consensus on an effective Px regimen. Some physicians report possible Px success with **paromomycin** (humatin) and **azithromycin** (ANH). | **Paromomycin**: nausea, reversible kidney toxicity and hearing loss. **Spiramycin**: vomiting, colitis. **Azithromycin**: see MAI. **Atovaquone:** nausea, rash and fever and increased liver function tests. **Octreotide**: nausea, diarrhea, malabsorption, headache. | **Atovaquone:** Take with fatty foods for proper absorption. |
| Px if symptomatic and CD4 < 300, or if asymptomatic and CD4 < 200 or 20%. Prefer oral drugs for Px or Mx, unless not tolerated, (or check on desensitizing), then use **aerosol pentamidine (AP)** 300mg./monthly. Post-PCP, if CD4 < 50 and symptomatic, aggressive docs/patients combine oral with AP. Oral: **TMP/SMX**: one dbl strength tablet 3x/wk, or once daily. **Dapsone**: 100 mg. 3x/wk or once daily. **Primaquine** 15 mg. 3x/wk. **Atovaquone** (CT). | **Pentamidine** (IV): low blood pressure and high blood sugar, low blood counts, elevated kidney and liver function tests, nausea, & pancreatitis. **AP**: cough, shortness of breath, pancreatitis. **TMP/SMX**: high rates of mild to severe allergic side effects: rashes, itching, nausea, fever, leukopenia, vomiting. **Dapsone**: similar allergic reactions, sensitivity to sunlight, headache, severe anemia (with G6PD deficiency), neuropathy. **Atovaquone**: see above. | **TMP/SMX**: interacts with ***warfarin, sulfonylureas, thiazide diuretics, phenytoin, methotrexate,*** and ***cyclosporine.*** Some physicians "desensitize" patients to **TMP/SMX** by starting with very low doses and gradually increasing. **Dapsone:** do not take within two hours of ***ddI*** as it will not be properly absorbed; also may interact with **rifampin, rifabutin, pyrimethamine** and **probenecid.** Atovaquone: see above. **Pentam. w/ *ddI:*** monitor for pancreatitis. ** |
| At risk if positive Toxo antibodies and CD4 count < 250 or 20%. Tx/Mx: **pyrimethamine** 25 - 50 mg./day with **sulfadiazine** 2 - 4 gm./day, and **leucovorin** 10 - 50 mg./day, if needed. **Dapsone**: 100 mg. 2x/wk. **Atovaquone**: promising, but not currently in trials for Toxo Px. In a recent CPCRA study, **pyrimethamine** was not effective as Px - but is still good for Tx and Mx. Best bet for Px is **TMP/SMX**, possibly **dapsone** or **atovaquone.** | **Pyrimethamine**: marrow suppression leading to anemia (monitor semiweekly). Use caution with convulsive disorders. Anemia risk in patients with G6PD deficiency. **Sulfadiazine**: skin rashes (sometimes severe) and itching, nausea, fever, leukopenia. **Clindamycin & azithromycin**: see MAC. **Atovaquone:** see Cryptosporidiosis. **TMP/SMX & Dapsone**: see PCP. | **Pyrimethamine**: ***leucovorin*** (folinic acid) may be given to decrease bone marrow suppression, particularly at high doses. **Pyrimethamine** may not be well absorbed with ***ddI.*** **Clindamycin**: avoid ***erythromycin.*** **Atovaquone**: unknown at this time. ** |
| At risk if positive CMV antibodies and CD4 count < 75 or 5%. Long term Mx necessary with Retinitis: **ganciclovir** 5 - 7 mg./kg., 5 - 7 days/wk. Switch to **foscarnet** if resistance develops. Oral **ganciclovir** (CT) Px/Mx. **Valacyclovir** (CT) Px. **MSL-109 + foscarnet or ganciclovir** (CT). | **Ganciclovir** (DHPG): confusion, disorientation, anemia, reversible neutropenia, thrombocytopenia, fever, abnormal liver function tests, rash. **Foscarnet**: anemia, may be very damaging to the kidneys, nausea, penile ulcerations in uncircumcised men. Serum creatinine and electrolyte level monitoring essential and can prevent irreversible damage. | **Ganciclovir**: *can use **G-CSF*** and ***GM-CSF*** to decrease neutropenia (low white blood cells). When combining w/ ***AZT*** or other neutropenic drugs, blood monitoring is essential; dose reduction or discontinuation could be necessary. Concurrent administration of saline solution has been reported to help prevent **foscarnet's** renal toxicities. **Ganciclovir** and **ddI**: monitor for pancreatitis. |
| Mx if recurrent HSV with **Acyclovir** 200 - 400 mg. 2 to 4/day. Higher doses if resistant (very high with HZV); possible extreme cases: monthly **foscarnet** induction. **Famciclovir, Valacyclovir** (CT). | **Acyclovir**: nausea, diarrhea, headache, skin rash. **Foscarnet**: see CMV. **Trifluridine** (TFT): transient burning & stinging. | **Foscarnet**: see CMV.<br>**** When taking broad spectrum antibiotics, monitor for fungal infections.** |

**Legend:**
**Tx** = Treatment
< = Less than
**Px** = Prophylaxis (prevention)
> = Greater than
**Mx** = Maintenance therapy
**CD4** = T4 Helper cell
**mg.** = milligrams
**IV** = intravenous

# More About Managing Opportunistic Infections

** There is evidence that cardiovascular toxicity may occur between Terfenadine (Seldane) and Astimezole (Hismanal), the Protease inhibitors and with several other prescription drugs used by people with HIV disease. These drugs are: Ketoconazole (Nizoral), Fluconazole (Diflucan), Itraconazole (Sporanox), Clarithromycin (Biaxin), Azithromycin (Zithromax), and Erythromycin. Check with your doctor if you are taking any of these drugs. For more information on drug interactions, call the Project Inform Hotline at 1-800-822-7422.

The chart on the previous pages is intended as a very general guide to managing opportunistic infections. Obviously, it can't substitute for a detailed discussion of each infection, and anyone dealing with one or more of these should call the Project Inform Hotline *(you can stop in to the Treatment Resource Center at AIDS Survival Project, we have all this information on file)* for more comprehensive information and then consult with your primary care provider.

If the standard drug for prevention or treatment fails, it may be necessary to try various experimental therapies. The prophylaxis and treatment of opportunistic infections is not an exact science, and often requires a certain amount of complicated trial-and-error to determine the best regimen for a particular patient.

There is often a noticeable gap between the therapies prescribed by experienced clinicians with large HIV practices and those prescribed by clinicians with less HIV experience. There may be occasions when patients will need to bring experimental therapies to the attention of providers who haven't previously used them.

The availability of various medications referenced on this chart can be problematic. A limited number are approved for specific HIV use; others are approved for non-HIV use but may be prescribed for HIV applications. Most are available either through clinical trials, expanded-access or compassionate-use programs. The access individuals have to prescription drugs may vary widely according to whether their health care is provided by private insurers or by government agencies.

Most of the phone numbers listed on the following pages are intended to be used by clinicians only, though inquiries by patients are sometimes answered. Aside from clinical trials, the only way a patient can access a special program is through their physician.

As more drugs have become available for the treatment and prevention of opportunistic infections, the possibility of drug interactions becomes ever greater and more important to consider. Most people are already aware of the interaction between AZT and ganciclovir which results in increased bone marrow suppression but many other drug interactions exist. Many drugs are metabolized (broken down) in the liver by a specific enzyme known as the p450 cytochrome and therein lie most of the problems. Drugs that require this enzyme to be metabolized can cause other drug levels to be substantially altered. Drugs that are metabolized in the liver include clarithromycin, azithromycin, rifabutin, fluconazole, itraconazole, nevirapine, the BHAP compounds, and the H2 blockers cimetidine (Tagamet) and ranitidine (Zantac). It is particularly important for people who are taking any of these drugs, especially for people with chronic liver disease, to monitor drug toxicity/efficacy and obtain specific drug levels in serum, if possible, so that, if necessary, dosages can be adjusted. For a complete list of potential drug interactions, please call the project Inform Hotline (1-800-822-7422) and ask for the Drug Interactions Fact Sheet.

# Options For Getting Medications You Cannot Afford , 7

## PATIENT ASSISTANCE NUMBERS

| DRUG | INDICATION | ACCESS | CONTACT INFO |
|---|---|---|---|
| ABLC (Amphotericin-B Lipid Complex) | Life threatening fungal infections | Compassionate use | 1-800-335-5476 |
| Acyclovir (Zovirax) | Herpes Simplex<br>Herpes Zoster | Patient Assistance | 1-800-722-9294 |
| Albendazole | Microsporidiosis | Compassionate use (MD's only) | 1-610-917-6454 |
| Alpha Interferon (Intron A) | KS & anogenital neoplasm | Patient Assistance | 1-800-521-7157 |
| Azithromycin (Zithromax) | MAI, Toxo, Crypto | Patient Assistance | 1-800-742-3029<br>1-800-869-9979 |
| Atovaquone (Mepron) | Toxo & PCP Treatment | Patient Assistance | 1-800-722-9294 |
| Cidofovir (Vistide) | CMV | Patient Assistance | 1-800-445-3235 |
| Ciprofloxacin (Cipro) | MAC, Bacterial Infection | Patient Assistance | 1-800-468-0894 ext. 5170 |
| Clarithromycin (Biaxin) | MAI | MD's Only<br>Patient Assistance | 1-800-688-9118 |
| Clindamycin (Cleocin) | PCP, Toxo | Patient Assistance | 1-800-242-7014 |
| Clofazimine (Lamprene) | MAC | Patient Assistance | 1-800-257-3273 |
| Didanosine (ddI) | HIV infection | Patient Assistance | 1-800-272-4878 |
| Dronabinol (Marinol) | Weight Loss | Patient Assistance | 1-800-274-8651 |
| Erythropoietin (Procrit) | AZT & HIV induced anemia | Patient Assistance | 1-800-553-3851 |
| Ethambutol (Myambutol) | MAC, Tb | Patient Assistance | 1-800-568-9938 |
| Fluconazole (Diflucan) | Fungal Infections | Patient Assistance | 1-800-869-9979<br>1-800-438-1985 |
| Foscarnet (Foscavir) | CMV, acyclovir resistant herpes | MD's Only | 1-800-488-3247 |
| Ganciclovir (Cytovene) | CMV | Patient Assistance | 1-800-444-4200<br>1-800-285-4484 |
| Ganciclovir Implants | CMV retinitis | Patient Assistance | 1-800-244-7668 |
| Ganciclovir Oral | CMV retinitis | Patient Assistance | 1-800-569-4630 |
| G-CSF & Epogen (Neupogen) | Neutropenia | General Information<br>Patient Assistance (MD's Only) | 1-800-282-6436<br>1-800-272-9376 |

## PATIENT ASSISTANCE CHART CONTINUED

| DRUG | INDICATION | ACCESS | CONTACT INFO |
|---|---|---|---|
| GM-CSF sargramostin (Leukine) | Neutropenia | Patient Assistance | 1-800-334-6273 |
| Indinavir (Crixivan) | HIV infection | Patient Assistance | 1-800-544-2987 |
| Isoniazid (Nydrazid) | Tb | MD's Only | 1-212-546-5709 |
| Itraconazole (Sporonox) | Histoplasmosis | MD's Only<br>Patient Assistance | 1-800-544-2987 |
| Ketoconazole | Fungal infections | Patient Assistance | 1-800-544-2987 |
| Lamivudine (3TC, Epivir) | HIV infection | Patient Assistance | 1-800-722-9294 |
| Liposomal doxorubicin (Doxil) | KS | Patient Assistance | 1-800-375-1658 |
| Liposomal gentamycin (TLC G-65) | MAC | Case by Case basis if failing on other meds | 1-609-951-4337 |
| Megestrol Acetate (Megace) | Weight loss | Patient Assistance | 1-800-233-0432 |
| Nystatin | Oral Candida | Patient Assistance | 1-800-544-2987 |
| Oxandrolone (Oxandrin) | Weight loss | | 1-800-741-2698 |
| Pentamidine (aerosol) | PCP Prophylaxis | Patient Assistance | 1-800-888-7704 ext. 8604 |
| Pyrimethamine (Daraprim) | Toxoplasmosis | Patient Assistance | 1-800-722-9294 |
| Rifabutin (Mycobutin) | MAI Prophylaxis | Md's Only | 1-800-366-5570 |
| Rifampin | Tb, MAC | Patient Assistance | 1-800-257-3273 |
| Ritonavir (Norvir) | HIV infection | Patient Assistance | 1-800-659-9050 |
| Sandostatin (octreotide) | Cryptosporidium and HIV related diarrhea | Patient Assistance | 1-800-447-6673 |
| Saquinavir (Invirase) | HIV infection | Patient Assistance | 1-800-282-7780 |
| Sparfloxacin | MAI, Tb | CT (pending FDA approval) | 1-800-521-3084 ext. 7297 |
| Stavudine (d4T) | HIV infection | Patient Assistance | 1-800-272-4878 |

## PATIENT ASSISTANCE CHART CONTINUED

| DRUG | INDICATION | ACCESS | CONTACT INFO |
|---|---|---|---|
| Streptomycin | Tb | Patient Assistance | 1-800-254-4445 |
| Sulfadiazine | Toxo | CDC | 1-404-488-4928 |
| Testosterone (Testoderm patch) | Hypogonadism | Patient Assistance | 1-800-321-3130 |
| TMP/SMX (Bactrim) | PCP Prophylaxis, acute PCP | Patient Assistance | 1-800-526-6367 |
| TMP/SMX (Septra) | PCP Prophylaxis, acute PCP | Patient Assistance | 1-800-722-9294 |
| Trimetrexate (Neutrixin) | PCP | Patient Assistance | 1-800-887-2467 |
| WihRho SD | ITP | Patient Assistance | 1-800-789-2099 |
| Zalcitabine (ddC) | HIV infection | MD's | 1-800-285-4484 |
| Zidovudine (AZT) | HIV infection | Patient Assistance | 1-800-722-9294 |

# FOOTNOTES

**Except where footnoted, this section was originally created by Robert Rockwell, M.D.**
*Thank you Dr. Rockwell*

1. by Ben Cheng, *PI Perspective*, April 1996

2 by Christopher D.L. Miller, R.N., May 1995

3 by Dave Thomson, Project Inform Kaposi's Sarcoma (KS) Addenda Sheet. April 1996

4 excerpted from a paper by Martin Majchrowicz, the complete paper is on file at the AIDS Survival Project Treatment Resource Center Summer 1996

5 *The NAPWA NEWS*, 1992

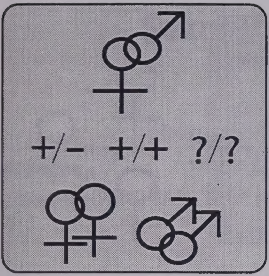
6 Project Inform, 4/29/96
Michael Wright, Principal Author

7 Compiled from lists published by AIDS Treatment Data Network and Project Inform. Updated by AIDS Survival Project September 1996.

This section was reviewed and updated September 1996 by Alicia A. Culver with input from Eric D. White, Treatment Resource Specialist, AIDS Survival Project and Wayne Deal, R.Ph., Patients Pharmacy & William Ramirez, MD.
*Thank you!*

# NOTES

# SAFER SEX



# PUTTING THE SEX INTO SAFER SEX!

Many people feel that sex is dangerous, and have become frightened of it. In fact, the sex most people enjoy is pretty safe. Almost all sex can be altered so that it is safer, greatly reducing or eliminating the risk of transmitting HIV and other sexual diseases.

It is time for people to make good decisions about sex based on good information, not scare tactics. Safer sex means educating yourself about the facts, then deciding what rules are right for you and what risks, if any, you are willing to take. Finally, it means communicating your rules to your partner and standing by them.

Safer sex is for everyone. It doesn't matter if you're gay, bi, straight. The virus doesn't have a clue and doesn't care about sexual orientation. It also doesn't matter if you are HIV+ or HIV-, because reinfection can occur with a stronger strain of the virus. Other diseases can be transmitted sexually and with a weakened immune system they can be very dangerous. Sexually transmitted diseases (including HIV) are transmitted through blood, semen, vaginal secretions, pre-cum, and breast milk. Any sexual activities which share these fluids are risky.

### 1. CAN WE TALK?...Sexual Communication

The most important safer sex practice is performed by the mouth. Talking about safer sex is the first step toward practicing safer sex. It is important for everyone to establish their sexual rules and communicate their limits to their partners. Decide for yourself what you're comfortable with and then let your partner know. SEX IS BETTER WHEN YOU DON'T HAVE TO WORRY! Talking about your sexual concerns with a friend is a great start to being able to talk about it with a partner.

### 2. RIGHT IN THE KISSER...Kissing

Saliva can NOT transmit HIV. Traces of the virus have been found in saliva, but not enough to infect someone. The only risk is the possibility of blood-to-blood contact if both partners are bleeding in their mouths or gums. Bleeding gums are common after brushing your teeth, so use mouthwash or mints to freshen your breath before sex.

### 3. FIRST FLOOR, GOING DOWN...Oral Sex

You can only transmit HIV if it gets into the bloodstream. It is not easy for HIV to get there through someone's mouth. Openings in the mouth (cuts, sores, etc.) may allow a partner's cum or vaginal fluids into the bloodstream, making oral sex more risky (see teeth brushing under kissing). Cumming into the mouth is riskier because of the increase in the amount of fluid. Using condoms will greatly reduce the risk (you can add flavor with jelly, honey, syrup, etc.) with male partners. With female partners, you can use dental dams (latex squares) or plastic kitchen wrap, microwaveable or regular will do nicely, thank you.

### 4. RIDIN' HIGH...Vaginal Intercourse

Vaginal intercourse without a condom is an effective way to transmit HIV. There are risks for both partners, however the risk is significantly greater for the woman. Using a latex condom and water-based lubricant will let her keep her fluids, and him keep his.

### 5. MOON OVER MY FANNY...Anal Sex

Anal Sex (in the ass) without a condom is very risky for both partners! Again, latex condoms and plenty of water-based lubricant, if used properly, will let each partner keep their own fluids.

### 6. LET YOUR FINGERS DO THE WALKING... Fingering/Fisting

Using hands and fingers to stimulate the vagina or rectum (ass) can be wonderful. If there are cuts or scrapes on the hand (think of that nasty old hangnail) there is an opening for fluids (blood or vaginal secretions) to enter the bloodstream. It is common for blood to be present when fisting (inserting the whole hand into hand into the vagina or rectum) due to stretching and tearing of the delicate linings. Latex gloves, with plenty of water based lube can make this safer. Keep in mind, five fingers makes a fist!

♂ ♂ ♂

7. SWINGING IN THE RAIN...Watersports, Scat, Rimming

Urine (pee) and feces (shit) do not contain enough HIV to transmit HIV, unless there is also blood present. Rimming (oral-anal contact) may not easily transmit HIV, but it can transmit other diseases such as hepatitis, amoebas, parasites, etc. To make rimming safer, use a dental dam or plastic wrap (see oral sex). Putting lubricant on the dam or plastic can help keep it in place. Just slick it, stick it, and lick it.

♀ ♀ ♀

8. YOU MADE ME LOVE YOU...S&M Scenes

It's not what you call it, it's what you do that counts. Anything that doesn't involve penetration or breaks in the skin is safe and poses no risk. If you're using razors or piercing needles, don't share them. If you're into bondage, it's a good idea to know the person tying you up. Your ability to maintain control may be difficult once you are restrained. Agree to code words in advance to stop the action. After all, "STOP, PLEASE" can mean (or not mean) many different things in the heat of submission.

## KEEP IT SLICK TO KEEP IT SLIDING!

Always use a **water-based lubricant** with latex condoms. This will help keep the condom from breaking (just think, all of that friction you're creating can hurt the big fellow!), and your mind on the pleasure.

Water-based lubricants such as KY Jelly can be found in just about every drugstore (and even most grocery stores). Sexual lubricants such as Astro-Glide, ForePlay, Wet, Comfort, etc. can be found in many specialty shops, as well as some drug stores.

## DO NOT USE OIL-BASED LUBRICANTS WITH LATEX CONDOMS

The two just don't get along. Oil-based products cause latex to disintegrate, making them useless. Some common oil-based items include petroleum jelly (vaseline), hand lotion, cold cream, and baby oil. Also, avoid food products that contain oil such as butter, margarine, whipped cream, etc. There is a difference between "water-based" and "water soluble". Water soluble means that it can be rinsed off in water, however it may still contain oil.

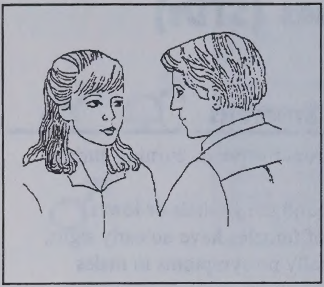
**LOOK FOR "CONDOM COMPATIBLE" OR "WATER-BASED" ON THE LABEL BEFORE USING.**

## NONOXYNOL-9

Many lubricants (and lubricated condoms) contain nonoxynol-9. Nonoxynol-9 has been shown in a test tube to kill sperm and HIV. However, in order to kill HIV, enough of it has to come into contact with the virus. There is no guarantee that it will happen in the body. **Lubricants containing nonoxynol-9 offer a secondary defense ONLY and must be used along with a latex condom.** Many people are allergic to nonoxynol-9, causing rashes which can provide a place for the virus to enter your bloodstream. Before using lubricants or condoms containing nonoxynol-9, test it by putting some on a sensitive part of your body (such as your inner-thigh area) and if any reaction occurs within an hour, do not use it.

# Sexually Transmitted Diseases (STDs)

| Disease | Symptoms |
|---|---|
| **Gonorrhea**<br>(also called GC, dose, clap, drip) | **Male:** pus discharge from the penis, burning during urination;<br>**Female:** pain in or around the genitals or lower abdomen About 80% of females have no early signs, and there are occasionally no symptoms in males |
| **Non-gonococcal urethritis**<br>(also called nonspecific urethritis, gleet) | Discharge from vagina or penis; painful and frequent urination in males; cervical bleeding in females, although many have no symptoms. |
| **Genital Herpes**<br>(also called Herpes Simplex Genitalis) | Minor rash or itching in the genital area at first, developing into painful blister-like, fluid-filled sores, with flu-like illness and swollen lymph glands. |
| **Crabs**<br>(also called cooties, lice) | Intense itching; pin-head blood spots on underwear; eggs or nits in pubic hair. |
| **Trichomoniasis**<br>(also called trich, TV, vaginitis) | **Male:** slight discharge or painful urination;<br>**Female:** heavy, odorous vaginal discharge, vaginal itching or soreness, burning urination;<br>Usually produces symptoms in females, but rarely in males. |
| **Venereal warts**<br>(also called genital warts) | Local irritation, itching, watery growths around genital and anal areas. |
| **Scabies**<br>(also called itch) | Intense itching; raised gray lines where mites burrow; red marks where mites surface. |
| **Syphilis**<br>(also called pox, bad blood, lues, syph) | First stage: a painless sore (chancre) at site of entry (usually genitals); Second stage: rash, sores, hair loss, flu-like illness, swollen joints; Latent stage: no symptoms. |
| **Hepatitis B**<br>(also called serum hepatitis) | Fever, loss of appetite, tiredness, jaundice (yellow color of eyes or skin), dark urine, gray-colored stools; other diseases can also cause some of these symptoms, and many persons have no symptoms of the disease. |
| **Acquired Immunodeficiency Syndrome**<br>(also called AIDS) | Weight loss; unexplained, persistent or recurrent fevers or night sweats; swollen glands (Lymph nodes); unexplained diarrhea or bloody stools; skin rashes or bruise-like marks on the skin; unexplained heavy, persistent, dry cough; other diseases also cause some of these symptoms. |



# How to Use a Condom

Sexual abstinence is the only 100% sure way to prevent pregnancy and sexually transmitted diseases, including HIV infection. If you do decide to have sex, correct use of a condom will help you to protect yourself and your partner against these risks. This guide tells you how to use a condom for maximum protection.

## HOW TO BUY CONDOMS

*Do* buy a supply of latex, reservoir (nipple) end, lubricated type condoms. They're available in different colors, textures, and sometimes in two different sizes. A good quality condom is the most important feature for safer sex.

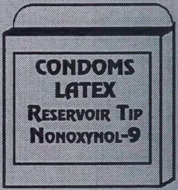
*Do* check expiration date on outer package.

*Do* check name of lubricant: it should contain nonoxynol-9, which provides a chemical barrier against sexually transmitted diseases.

*Do* store in a cool dry place.

*Do* carry a condom with you at all times.

*Don't* buy condoms made of any material other than latex. (Only latex prevents passage of harmful germs.)



*Don't* buy old (outdated) condoms.

*Don't* store condoms in hot glove compartment of car. Heat can damage the condom.

*Don't* carry in hip wallet for long periods of time--this shortens shelf life.

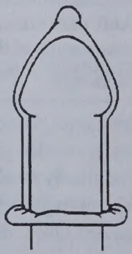
*Don't* be shy about buying condoms--40% are sold to women.

## HOW TO PUT THE CONDOM ON

*Do* remove rolled condom from package.

*Do* roll condom down on penis as soon as it is hard, *before* you start to make love (foreplay).

*Do* leave 1/4-1/2 inch extra space at tip of condom to catch the ejaculate if the condom has no nipple.



*Don't* unroll condom; instead, carefully roll on all the way toward the base of the penis.

*Don't* put condom on only when you are ready to enter your partner--it may be too late. Drops of semen may ooze from the uncovered penis before ejaculation, and may infect or impregnate your partner.

*Don't* twist, bite, or prick condom with a pin--this will damage it and allow fluid to leak out, possibly infecting your partner.

## HOW TO TAKE THE CONDOM OFF

***Do*** hold the condom at the rim; remove soon after ejaculation.

***Do*** keep used condom away from partner's genitals and other areas of the body as well.

***Don't*** let penis go soft inside partner--condom may drop off, and protection is lost.

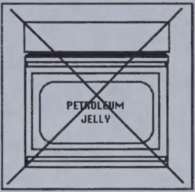
***Don't*** tug to pull condom off--it may tear.

***Don't*** allow semen to spill on your hands or body. Wash hands or body parts if contact occurs. Wrap condom in tissue and dispose of safely.

***Don't*** allow semen to come in contact with a skin break, cut, or open wound.

## SPECIAL POINTS TO REMEMBER

- If you buy unlubricated condoms, you may need to buy a lubricant. Use only water-soluble lubricants such as spermicidal jelly or water.
- Don't use oil-based lubricants such as petroleum jelly or vegetable oil with latex condoms, since they can damage the condoms.
- Never use a condom more than once.
- Correct use of condoms increases comfort, and promotes a sense of security in having safer sex.



## HOW TO TALK ABOUT CONDOMS WITH A RESISTANT, DEFENSIVE, OR MANIPULATIVE PARTNER

| **If your partner says:** | **You can say:** |
|---|---|
| "I'm on the Pill, you don't need a condom." | "I'd like to use it Anyway. We'll both be protected from infections we may not realize we have." |
| "I *know* I'm clean (disease-free); I haven't had sex with anyone in months." | "Thanks for telling me. As far as I know, I'm disease-free, too. But I'd still like to use a condom since either of us could have an infection and not know it." |
| "I'm a virgin." | "I'm not. This way we'll both be protected." |
| "I can't feel a thing when I wear a condom; it's like wearing a raincoat in the shower." | "Even if you lose some sensation, you'll still have plenty left." |
| "I'll lose my erection by the time I stop and put it on." | "I'll help you put it on--that'll help you keep it up." |
| "By the time you put it on, I'm out of the mood." | "Maybe so, but we feel strongly enough for each other to stay in the mood." |
| "It destroys the romantic atmosphere." | "It doesn't have to be that way." |
| "Condoms are unnatural, fake, a total turnoff." | "Please let's try to work this out--an infection isn't so great either. So let's give the condom a try. Or maybe we can look for alternatives." |
| "What kinds of alternatives?" | "Maybe we'll just pet, or postpone sex for a while." |
| "This is an insult! Do you think I'm some sort of disease-ridden slut (gigolo)?" | "I didn't say or imply that. I care for you, but in my opinion, it's best to use a condom." |
| "None of my other boyfriends uses a condom. A *real* man isn't afraid." | "Please don't compare me to them. A real man cares about the woman he dates, himself, and about their relationship." |
| "I love you! Would I give you an infection?" | "Not intentionally. But many people don't know they're infected. That's why this is best for both of us right now." |
| "Just this once." | "Once is all it takes." |
| "I don't have a condom with me." | "I do." or "Then let's satisfy each other without intercourse." |
| "You carry a condom around with you? You were planning to seduce me!" | "I always carry one with me because I care about myself. I have one with me tonight because I care about us both." |
| "I won't have sex with you if you're going to use a condom." | "So let's put it off until we can agree." or "OK, then let's try some other things besides intercourse." |

# FOOTNOTES

This section was compiled by Jim Sacco, LCSW. 1992

Updated by Alicia Culver and Joe Wright. May 1995